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ABSTRACT

A feasibility study regarding the training and information needs of preschool and day care administrators, staff, and teachers regarding HIV/AIDS was conducted. This study also examined the issues associated with the presence of HIV-positive children in preschool and day care settings and the need for designing a program to help preschools and day care centers to develop a comprehensive and proactive policy. Parents and teachers of HIV-positive preschoolers were interviewed, and focus groups made up of parents, teachers, and day-care providers were formed. The study's objectives were as follows: (1) identify the policy, information, and education needs of preschools, day care centers, and their constituencies; (2) determine the best means to address the needs of preschools, day care centers, and their constituencies; (3) investigate the best way to package and deliver information and training needs for the target audience; and (4) identify the appropriate dissemination channels for the proposed package. The chapters in the report are: (1) "Phase I Activities," including a discussion of background literature, designing team meeting and focus groups, and outcome of activities; (2) "HIV/AIDS and Early Childhood Education: Background and Issues," covering special challenges, epidemiological trends, social and legal issues, barriers, psychosocial effects, and proactivity case studies; and (3) "Design Plan," focusing on the target audience, guiding principles, proposed product design, major content areas, commercial application, and anticipated outcome. A bibliography listing 108 references is provided. (BGC)

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HIV/AIDS in Early Childhood Day-Care Settings

FINAL REPORT

Phase I

National Institutes of Health
National Institute of Child Health and Human Development
SBIR Grant #1 R43 HD31836-01

David D. McKinney, Ph.D.
Principal Investigator

VSA Educational Services

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HIV/AIDS
in Early Childhood Day-Care Settings

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April 14, 1995

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INTRODUCTION

VSA Educational Services undertook this Phase I feasibility study to explore the issues associated with the presence of HIV-positive children in preschool and day-care settings and determine the need for a program to help preschools and day-care centers to develop a comprehensive, pro-active policy. In addition to examining the information and skills needs of early childhood educators, we investigated the utility of video as a training mechanism and identified potential industry partnerships for marketing and disseminating the final product.

The extent of our research on this issue is unprecedented. To fully understand the issues, we reviewed recent literature on medical, psychosocial, and education issues related to Pediatric AIDS. We conducted comprehensive searches using the BRS and DIALOG databases, the National School Boards Association's HIV resource database, the National Center for Education in Maternal and Child Health database, and the databases available through the Center for Disease Control and Prevention's (CDC) National AIDS Clearinghouse. To put these issues in focus, we interviewed the parents and teachers of HIV-positive preschoolers, and we conducted focus groups with parents, preschool teachers, and day care providers. We corroborated our findings by consulting extensively with nationally recognized experts in the fields of Pediatric AIDS, early child development, health education, and teacher training.

Our Phase I investigations reveal that preschool educators are clearly unprepared to work with the HIV-positive child. But we also found that preschool educators want to be prepared. Currently, there are no practical materials that address the full spectrum of issues which HIV-positive children bring to the preschool setting.

To meet this need, VSA Educational Services proposes to develop a comprehensive package of materials for preschools and day care centers. Intended for individuals and organizations that work with 3- to 6-year-old children, the package will help parents, administrators, teachers, and other school staff respond proactively with knowledge, skill, and compassion to children with HIV/AIDS.

FUNDING

Funding for the Phase I feasibility study was provided through the Small Business Innovation Research (SBIR) Program of the Public Health Service, U.S. Department of Health and Human Services. The award was administered by the National Institute of Child and Human Development (NICHD), National Institutes of Health. A renewal of funding for Phase II is being sought to implement the design plan created under Phase I.

OBJECTIVES

In undertaking this feasibility study, VSA Educational Services sought to investigate the specific information and training needs of preschool and day-care administrators, staff, and teachers regarding HIV/AIDS and to develop a preliminary design for a training package that would address these needs. The objectives of the study were:

1. Identify the policy, information, and education needs of preschools, day-care centers, and their constituencies.

2. Determine the best means to address the needs of preschools, day-care centers, and their constituencies.

3. Investigate the best way to package and deliver information and training needs for the target audience.

4. Identify the appropriate dissemination channels for the proposed package.

SUMMARY OF PHASE I ACCOMPLISHMENTS

In determining the viability of the proposed product, VSA Educational Services successfully accomplished the following:

- Identified, reviewed, and analyzed the literature relating to HIV/AIDS, schools, and young children including, but not limited to epidemiology, infection control, legal issues, education, emotional issues (e.g., fear, loss, etc.), and parental concerns.

- Identified and interviewed the top health care providers, practitioners, experts, and researchers, as well as a sampling of parents, teachers, administrators, and advocates regarding HIV/AIDS issues and preschool settings.

- Reviewed existing and emerging technologies as possible delivery options for the training program; searched the literature to determine future trends in technology that would impact on the product; and evaluated findings against surveys of the target audience to determine the most appropriate technology for delivery of the training package.

- Conducted a Design Team meeting to determine the design principles to guide development of the product.

- Conducted a Focus Group to test the initial design and delivery mechanism for the proposed program.

- Convened an Advisory Board to review the work of the Design Team and the findings of the Focus Group to determine if changes should be made in the preliminary design.

- Produced the feasibility study which summarized research and provided detailed specifications for the proposed training program and appropriate channels for dissemination.

The report which follows details our research efforts and outlines our approach to product design, testing, and development. For simplicity's sake, the terms "preschool" and "early childhood" are used interchangeably to denote group education settings for 3- to 6-year-olds in public school and community-based (both profit and non-profit) programs.

CHAPTER 1

PHASE I ACTIVITIES

The activities described below indicate the process by which VSA Educational Services developed the initial design specifications for the proposed comprehensive package of materials for preschools and day-care centers. The purpose of these activities was:

1. To determine the information needs of early childhood educators regarding HIV/AIDS as it relates to preschoolers and preschool and/or day-care classes.

2. To ascertain the current state of training of early childhood educators regarding HIV/AIDS.

3. To develop a preliminary design plan for an HIV/AIDS training package that can be used in preschools and day-care centers to help administrators, teachers, school staff, and parents respond proactively with knowledge, skill, and compassion to the needs of children who have HIV/AIDS.

Toward these goals, VSA Educational Services:

- Conducted an exhaustive search of the literature;
- Identified researchers, practitioners, individuals from the target audience, and other interested parties to interview;
- Developed an interview instrument;
- Conducted telephone interviews with interested parties across the country;
- Conducted a Design Team meeting;
- Conducted an Advisory Committee meeting:
- Conducted a Focus Group of preschool teachers and day-care providers;
- Investigated promotion and delivery options;
- Drafted a preliminary design document; and
- Compiled a final report.

LITERATURE REVIEW

VSA Educational Services undertook an extensive search of resources related to Pediatric AIDS, including physical, cognitive, and psychosocial disabilities, AIDS in the preschool setting, grief counseling, infection control, and universal precautions. The literature review was undertaken independently by Patricia Davenport, HIV/AIDS Consultant for VSA Educational Services. Ms. Davenport's research was intended as a check against the interviews and curriculum development process to ensure that the activities of the study were sound.

This review included on-line searches of the following databases: Dissertation Abstracts, ECER (Exceptional Children Education Resources), ERIC (Educational Resources Information Center), and PsycINFO (Psychological Abstracts Information Services). Subject searches for monographs and analytics were conducted through ALADIN, the online catalog for the Washington Research Library Consortium which includes American, Catholic, Gallaudet, George Mason, George Washington, Marymount, and the District of Columbia universities. Additional searches were conducted through the National AIDS Clearinghouse, National Library of Medicine, Child Welfare League of America Clearinghouse, and National School Boards Association.

Research in these areas is reported in major professional journals including: *AIDS Education and Prevention, American School Board Journal, Childhood Education, Children Today, Day Care and Early Education, Family Relations, Journal of School Health, Mental Retardation, Pediatrics,* and *Young Children.* (See Appendix A for a selected bibliography on the psychosocial, medical, and legal aspects of HIV/AIDS in preschool and day care settings.)

In addition to these journals, research on Pediatric AIDS has been reported in various monographs and special reports. These reports include, but are not limited to, publications of the Centers for Disease Control, Child Welfare League of America, Council for Exceptional Children, National Association for the Education of Young Children, National Association of State Boards of Education, National Leadership Coalition on AIDS, and Pediatric AIDS Foundation.

To supplement the published research, we contacted researchers in the fields of Pediatric AIDS and education to obtain copies of works in progress. In addition, we obtained copies of program and curricular materials regarding HIV/AIDS education.

The research data was summarized and given to the Design Team for their consideration along with summaries of the other activities. The Design Team then determined the information and delivery based on all findings and developed an outline for the package and its constituent components.

The combined findings of this research are outlined in Chapter 2.

DEVELOPMENT OF AN INTERVIEW INSTRUMENT

Another important step in the feasibility study was the design of an interview instrument to guide discussions of the proposed package with parents, preschool teachers, and experts. The format of the interview instrument was designed to cover all aspects of the feasibility study (including the HIV-positive child, preschool teacher, classroom environment, and training needs). The interview protocol was kept flexible so that conversation could focus on the interviewee's individual experience and expertise. The format featured open-ended questions and allowed us to evaluate concepts identified in the literature as well as to solicit new ideas and practices.

A copy of the interview instruments is included in Appendix B.

IDENTIFICATION OF PARENTS, EARLY CHILDHOOD EDUCATORS, AND EXPERTS

We conducted interviews with three different groups: parents of children with HIV/AIDS, early childhood educators, and experts. A total of 17 interviews were conducted. Interviewees were representative of every region of the United States, located in 13 states and the District of Columbia (see Chart 1). Interviews took an average of 1 to 1.5 hours. While structured to capture information on all the target questions, the interviews were flexible in order to allow the interviewees to expand on those areas in which they had the greatest experience. Through this variable format, we were able to learn much about the ongoing research, as well as the current level of knowledge among teachers and staff.

Our first group were parents of children with HIV/AIDS who are currently or have recently been in early childhood settings. We selected parents of children who had attended both mainstreamed preschools and in settings exclusively for children with special needs. We maintained the anonymity of the parents to allow them to speak freely about their experiences. All of the children of the parents we interviewed had been diagnosed with the HIV virus either at birth or within a year after birth.

Our second group of interviewees were early childhood educators. We maintained the anonymity of the preschool teachers to provide them with a protected environment where they could speak freely. As part of the selection process, we identified teachers who represented the diversity of the target audience. Two interviewees had previous experience with classes that contained students identified with HIV/AIDS. We interviewed persons who had experience with different demographics, and our interviewees represented both public and private early childhood centers in urban, suburban, and rural areas across the country. The teachers had a broad range of teaching experience, from a teaching student to preschool directors with 17 years of experience. (See Charts 2-3.)

We interviewed six experts, whose experience included Pediatric AIDS, HIV in education settings, training/training development, early intervention, and AIDS policy development. Many had HIV/AIDS experience including teacher training, training HIV-positive individuals to be classroom presenters, and training service providers who work with HIV-positive children and families. (See Charts 4-6.)

The following persons were interviewed as experts:

Susan Chalfin, Ph.D., Director, Developmental Services Program, Mailman Center for Child Development.

Kevin Cranston, M.DN., AIDS/HIV Program Director, Massachusetts Department of Education, Learning Support Services.

Sandra Lewis, Psy.D., Psychologist Educator, National Pediatric HIV Resource Center.

Gail Maurer, Consultant, HIV Prevention Education, Healthy Kids, Healthy California Office.

Mary McGonigle, M.F., Consultant, AIDS Action Foundation.

Pam Tollefsen, M.Ed., Program Supervisor, HIV/STD Prevention and Comprehension Health Education, Washington State.

Summaries of the interviews can be found in Appendix C.

CHART 1 - Interviews by State

CHART 2 - Early Childhood Educator's Experience in Early Childhood Education in Years

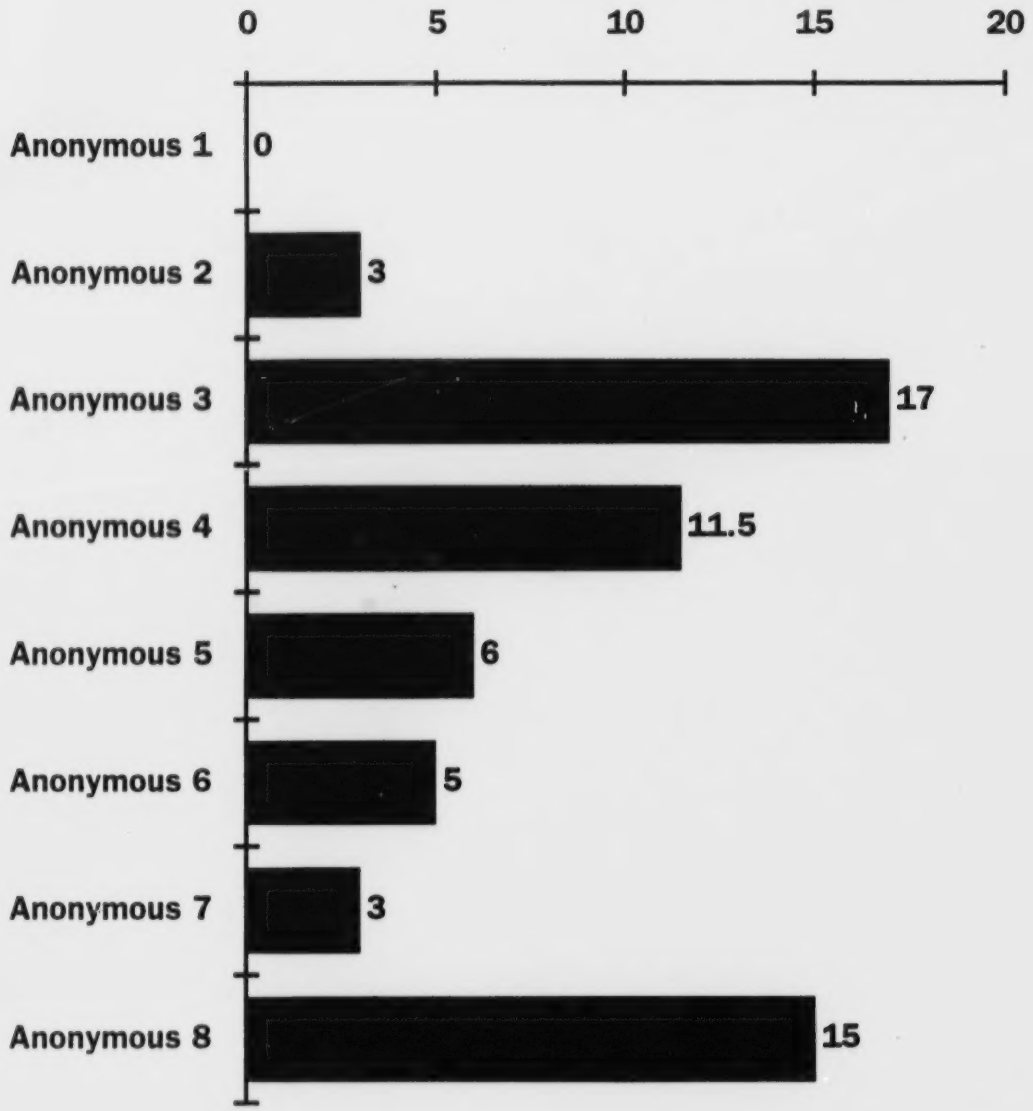


CHART 3 - Early Childhood Educators' Experience in Training/Training Development in Years

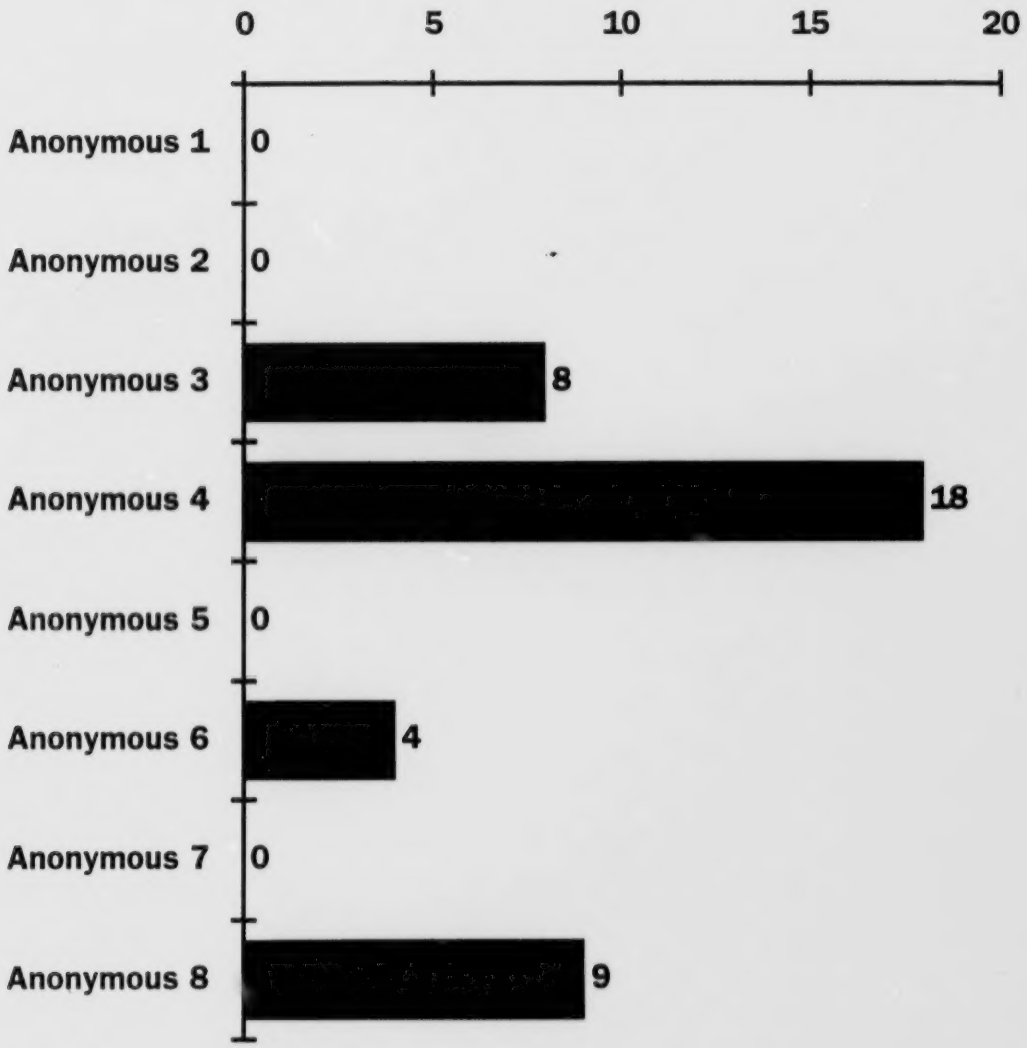


CHART 4 - Experts' Areas of Expertise

	Pediatric AIDS	HIV in Education Settings	Training/Training Development	Early Intervention	Policy Development
Susan Chalfin	●		●	●	
Kevin Cranston	●	●	●		●
Sandra Lewis	●		●	●	
Gail Maurer		●	●		
Mary McGonigle	●		●	●	●
Pam Tollefsen		●	●		

CHART 5 - Experts' Experience in Pediatric AIDS in Years

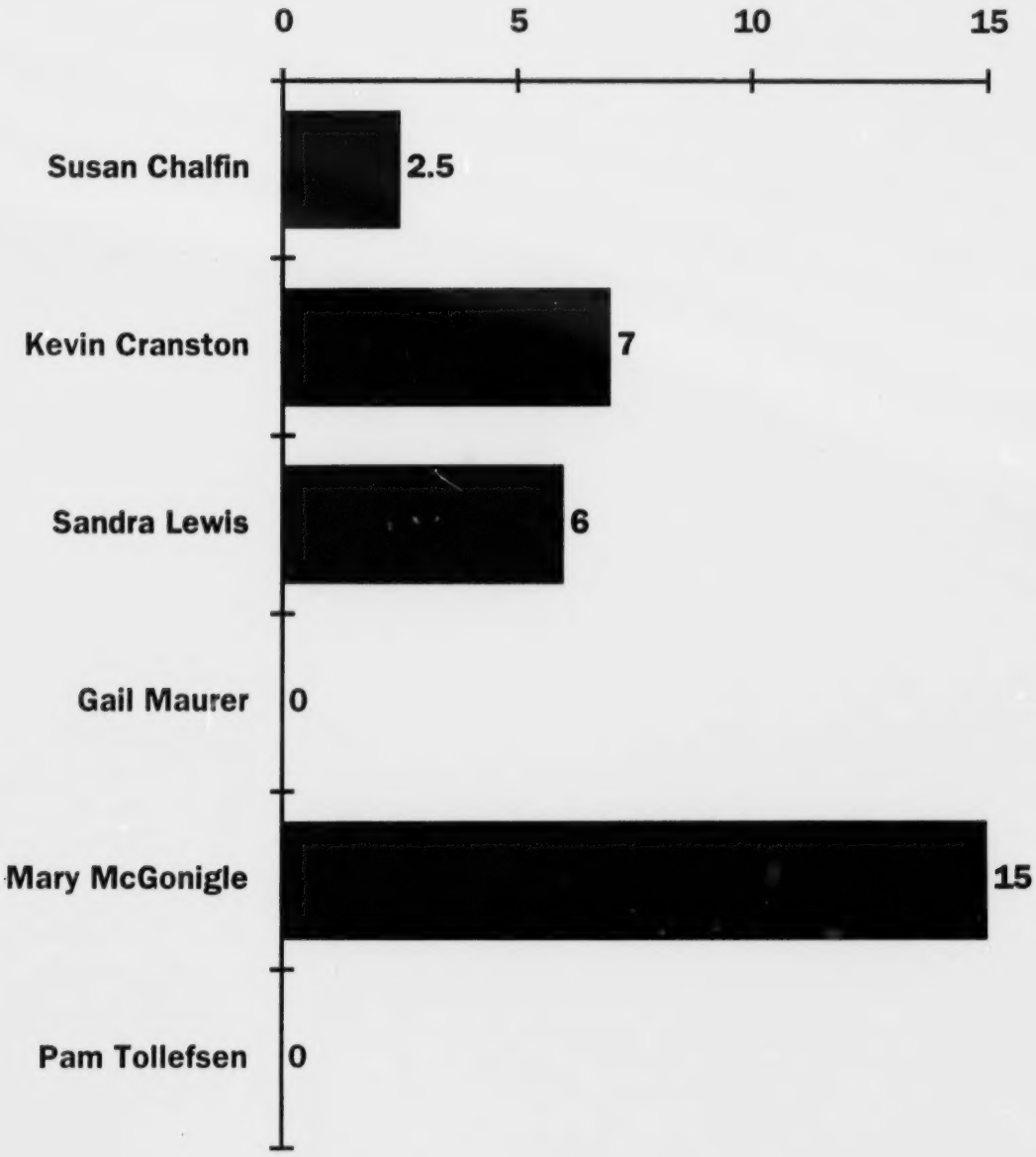
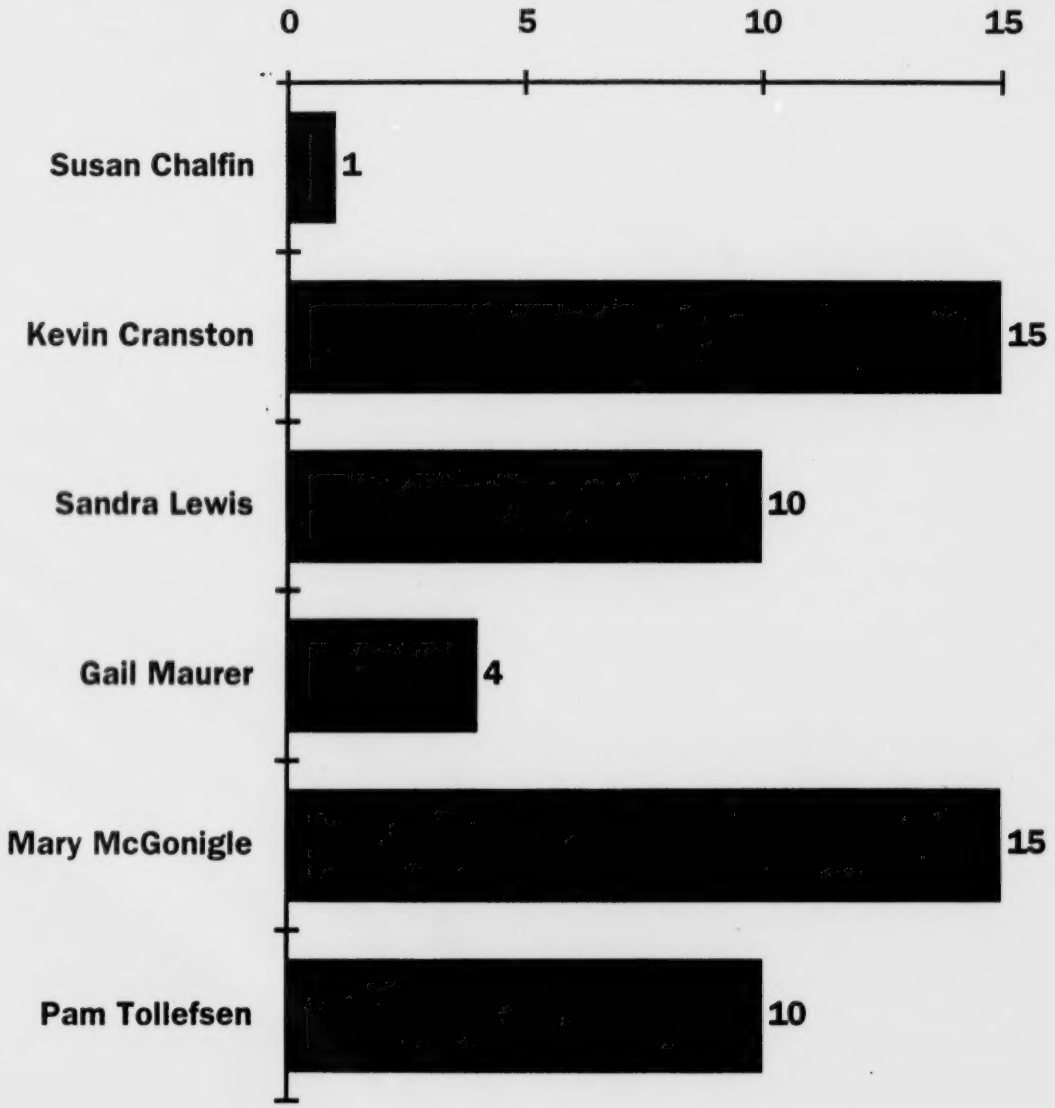


CHART 6 - Experts' Experience in Training/Training Development in Years



DESIGN TEAM MEETING

After completing the literature review and conducting the interviews, we synthesized our findings in preparation for the Design Team meeting. We selected Design Team members because of their expertise in Pediatric AIDS, AIDS in school settings, and early childhood education. (A summary of this information is included in Chart 7.)

To fully acquaint the Design Team members with the scope of the study, we wrote a report summarizing our findings to date for distribution to the participants. This report was intended to focus attention on the issues identified during the research phase and to stimulate discussion at the meeting.

The Design Team was charged with four objectives:

- To identify the specific issues surrounding AIDS/HIV in early childhood education settings;
- To determine the content areas for the proposed program;
- To develop a preliminary design for the training package; and
- To determine the best means for delivery and dissemination of the training package.

The Design Team members are:

James Bodgen, M.P.H., Project Director, HIV/AIDS Policy and Education, National Association of State Boards of Education.

Patricia Davenport, HIV/AIDS Consultant, VSA Educational Services.

Jean Emery, LICSW, AIDS Curriculum Developer, Child Welfare League of America.

Mary Hartzell, Director, First Presbyterian Nursery School, Santa Monica, California.

Karen Hennessy, RN, CPNP, AIDS Specialist, VSA Educational Services.

David D. McKinney, Ph.D., Principal Investigator, VSA Educational Services.

Patricia Spahr, Director of Information Development and AIDS Education Coordinator, National Association for the Education of Young Children (NAEYC).

Minutes from the Design Team meeting are found in Appendix D, and the results of the Design Team meeting are incorporated into this study.

CHART 7 - Design Team Areas of Expertise

	Pediatric AIDS	HIV in Education Settings	Training/Training Development	Early Intervention	Policy Development
James Bodgen	●	●	●		●
Patricia Davenport	●		●		●
Jean Emery	●	●	●	●	●
Mary Hartzell	●	●	●		●
Karen Hennessy	●		●	●	●
David McKinney		●	●	●	●
Pat Spahr	●	●	●	●	●

FOCUS GROUP

Since a training program that helps administrators, teachers, and other school staff respond proactively with knowledge, skill, and compassion to the needs of children with HIV/AIDS cannot succeed unless it meets the needs of the potential target audience, VSA Educational Services conducted a Focus Group to review the initial design of the training package.

The Focus Group involved parents, preschool teachers, and administrators from the DC, Maryland, and Virginia area. Participants came from private school settings, church-sponsored programs, and public Head Start programs. The range of teaching experience ranged from 1.5 years of experience to 32 years of experience. At least one of the participants did have previous experience with HIV/AIDS in the classroom. (See Chart 8.)

After a brief introduction by David D. McKinney, Principal Investigator for the project, a sample unit of the proposed training package was presented to the group. The presentation closely simulated our proposed design for the training package. Karen Hennessy served as facilitator using a combination of lectures, activities, and video segments to illustrate points. The combination closely resembles the videodisc-based training that our research indicated as the most effective delivery mechanism (e.g., easy access to material, ability to freeze-frame, etc.). All parts of the training were interactive which gave the facilitator the freedom to tailor training to meet specific needs of the audience. Training was designed to

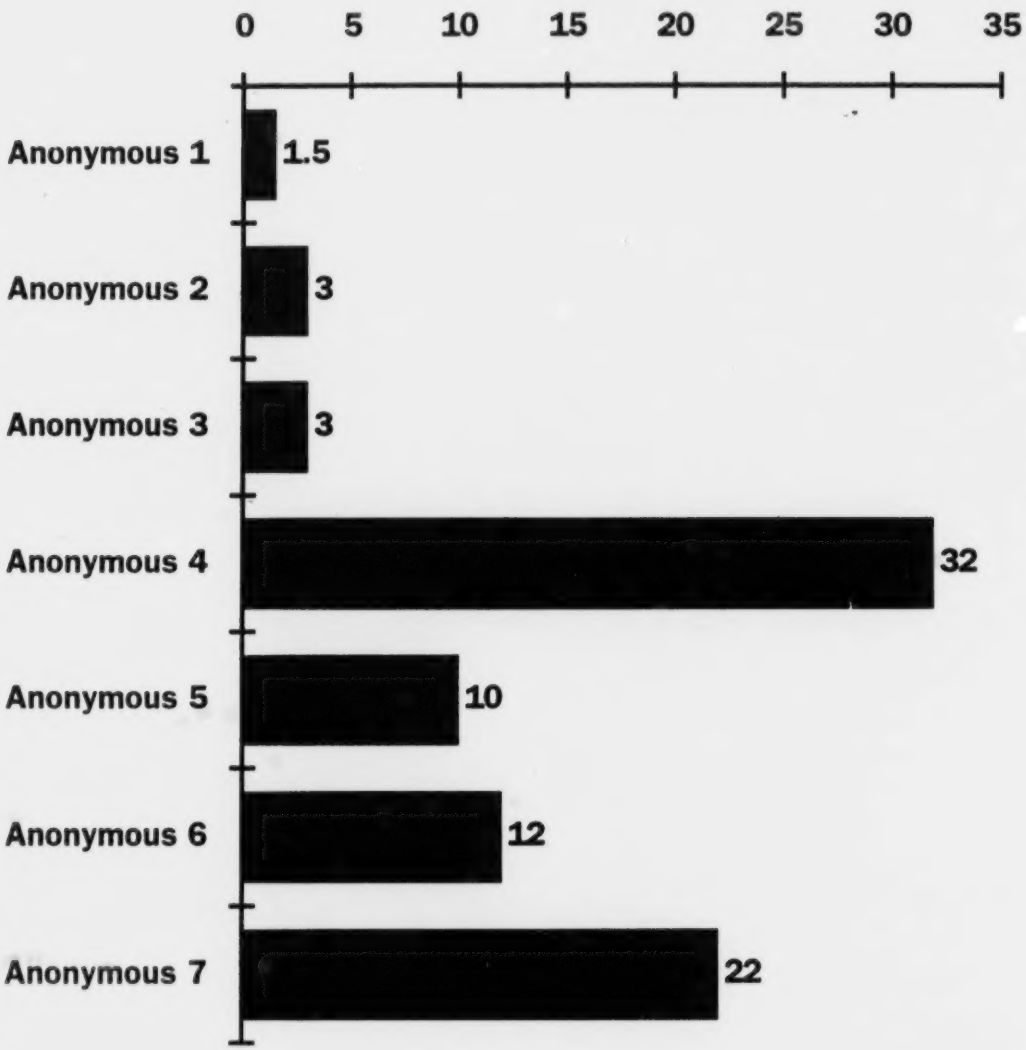
1. Identify needs, concerns, and fallacies held by the audience;

2. Address these needs, concerns, and fallacies; and

3. Empower the audience to proactively put into place procedures that ensure a healthy and nurturing environment for all students, including children with HIV/AIDS.

A summary of the Focus Group can be found in Appendix E.

CHART 8 - Focus Group Participants' Experience in Early Childhood Education in Years



ADVISORY COMMITTEE MEETING

We convened an Advisory Committee meeting to review the results of research and our product design. We selected participants for the Advisory Committee because of their expertise in Pediatric AIDS, teacher training, and early childhood education. (A summary of this information is included in Chart 9.)

We supplied the Advisory Committee members with minutes from the Design Team meeting and our proposed product design. These materials were intended to provide background on the study and to provide the criteria for evaluating the work of the Design Team.

The Advisory Committee was charged with two objectives:

- To review the specific issues surrounding HIV/AIDS in the early education setting identified by the Design Team meeting to ensure adequate addressing of needs; and
- To review the preliminary design for the training package as developed in the Design Team meeting.

The Advisory Committee members are:

Constance Cordovilla, M.A., AIDS Education Coordinator and Project Director, American Federation of Teachers (AFT).

Allen Crocker, M.D., Associate Professor of Pediatrics, Harvard Medical School and Senior Associate in Medicine at Boston Children's Hospital.

Nancy Peddle, Executive Director, International Society for Prevention of Child Abuse and Neglect (ISPCAN), and Chair, Board of Directors, National Ecumenical Child Care Network.

Celestine Diggs Smith, Disability Coordinator, Head Start, District of Columbia.

Lori Wiener, Ph.D., Coordinator, Pediatric HIV Psychosocial Support Program, National Cancer Institute.

The Committee reviewed the design plan submitted by the Design Team and offered suggestions for refinement which were incorporated into a revised design.

OUTCOME OF ACTIVITIES

The activities resulted in a broad-based outline of the issues related to HIV/AIDS and early childhood programs. This outline was used to govern the development of the study and the design of the proposed training package. Both the research and the design plan are detailed in the following chapters.

CHART 9 - Advisory Committee Areas of Expertise

	Pediatric AIDS	HIV in Education Settings	Training/Training Development	Early Intervention	Policy Development
Constance Cordovilla	●	●	●	●	●
Allen Crocker	●	●	●	●	●
Patricia Davenport	●		●		●
Jean Emery	●	●	●	●	●
Karen Hennessy	●		●	●	●
David McKinney		●	●	●	●
Nancy Peddle		●	●	●	●
Celestine Smith		●	●	●	●
Lori Wiener	●	●	●	●	●

CHAPTER 2

HIV/AIDS AND EARLY CHILDHOOD EDUCATION: BACKGROUND AND ISSUES

EARLY CHILDHOOD EDUCATORS AND HIV/AIDS

"Nobody Prepared Me For This!"

This reaction from a public school health official interviewed by Lavin and colleagues (1994) epitomizes the frustration and anxiety felt by many preschool educators at the prospect of caring for an HIV-positive child. HIV/AIDS raises complex psychosocial, legal, and medical issues for early childhood educators. From reviewing the current literature, interviewing preschool educators and parents, and consulting with experts, we found that preschool educators remain woefully unprepared to meet these challenges.

Our research also reveals that preschool educators are willing to work with the HIV-positive child, if given enough information, training, and support. All preschool teachers want to provide a "warm and loving" environment for the children in their care (Willer et al., 1991). Teachers who care for HIV-positive children are no exception. But while teachers may be feeling less threatened than they used to about the subject of HIV/AIDS (Brucker & Hall, 1991), they remain uncertain about their ability to meet an HIV-positive child's emotional needs and prevent HIV transmission in the classroom. Some teachers may not even believe they need this information unless they know a student has HIV/AIDS (Ballard, White, & Glascoff, 1990; Jessee, Nagy, & Poteet-Johnson, 1993; Morrow et al., 1991; Rubinstein, 1986).

Specifically, teachers want to know how to prevent the spread of infectious diseases, handle potential blood exposure situations, and provide age-appropriate HIV/AIDS education. They want school policies that tell them explicitly how to handle school attendance and confidentiality issues. And they want to know how other schools have handled these matters (Crowley, 1990; Kerr, Allensworth, & Gayle, 1989; Nelson, & Hendricks, 1988; Palfrey et al., 1994).

NEED FOR COMPREHENSIVE, PRACTICAL INFORMATION

Research further indicates that there is nothing which adequately addresses these concerns in a practical way. Much of what is available on the subject of HIV-positive preschoolers is theoretical information in the form of monographs and

journal articles. Technical assistance materials also exist, but they only focus on specific aspects of the challenge. (See Appendix A: Select Bibliography).

There are a few materials that teach preschool children about HIV/AIDS, but most target older children and adolescents. Other materials advise parents on how to talk to their children about HIV/AIDS, but these seldom address the 3- to 6-year-old specifically. There are manuals for teachers that outline infection control practices and discuss the medical and psychosocial needs of HIV-infected children, but few of these resources examine the HIV-positive preschooler exclusively. Materials also exist on advocacy and school HIV/AIDS policy development, but again, the special issues of the preschool and group day-care setting are never addressed in depth.

Members of our Design Team and Advisory Committee, who have authored many of these materials, agree that there is nothing that provides a range of information needed by preschool educators to prepare for and work with HIV-positive children. School administrators need "how to" templates for developing policy; teachers require information that is relevant to everyday preschool and day-care activities. Teachers also need "hands on" skills development and opportunities to overcome any anxiety they have about working with an HIV-infected child.

SPECIAL CHALLENGES OF THE PRESCHOOL SETTING

HIV-specific issues faced by educators are compounded by the unique circumstances of the preschool setting. First, the prevalence of communicable diseases is higher among preschoolers than among older children. There is more close, physical contact between children and between teacher and child in the preschool setting. A related problem is that 3- to 6-year-olds have less control over their body functions than older children. This age group is described by a Pediatric AIDS researcher as follows: "They have a lot of runny noses, they drool and they mouth everything, and they're generally rather non-hygienic" (Okie, 1990).

Another unique aspect of the preschool environment is the meaning it has for parents. Mary Hartzell, a Design Team member and Director of First Presbyterian Nursery School (Santa Monica, California), noted that parents are likely to be especially protective of their children and anxious about any perceived health threat because preschool and day-care represents the child's first time away from home. A day-care teacher in our focus group wondered, "How on earth do I reassure parents?...It's not so much the other kids—it's the parents. The moms are already going through changes about their child being out of their sight."

To help preschool educators meet these challenges, we must understand the emotional, legal, and medical implications of HIV/AIDS for the preschool environment. First, we will examine the epidemiological trends which make this such a pressing issue. Then, we will look at the social and legal issues which have shaped school responses to HIV-positive children. We will evaluate the preparedness of preschools and day-care centers for the presence of HIV-positive

children. Next, we will revisit common misconceptions about HIV transmission which prevent practical responses to these issues. We will then discuss the history of Pediatric AIDS, its psychosocial effects, and the implications of these issues for the preschool educator. Finally, we will discuss the information, training, and support needed by preschool educators to prepare for and work with the HIV-positive child.

EPIDEMIOLOGICAL TRENDS

More HIV-Positive Preschoolers

Pediatric AIDS (age 13 and under) now ranks as the fastest growing exposure group (Osmond, 1994b). Based on serosurveys of childbearing women, scientists have determined that each year 1,500 to 2,000 children are born who will eventually develop HIV/AIDS (Simonds & Oxtoby, 1995). Currently, half of these children survive into school age; some even reach adolescence. As better drugs are developed to slow virus replication and treat the complications of AIDS, more HIV-positive children are living longer and attending preschools and day-care centers (Ammann, 1994; Cohen, Papola, & Alvarez, 1994; Meyers, 1994; Palfrey et al., 1994; Papola, Alvarez, & Cohen 1994). These statistics speak to the need to act now.

HIV Affects Everyone

Pediatric AIDS is a reality nationwide. No community is immune. Between July 1992 and June 1994, 992 children nationwide were diagnosed with AIDS (CDC, 1994). Rich or poor, large or small—communities all around the country are experiencing the HIV epidemic. Although the prevalence of Pediatric AIDS is highest in cities like New York, Miami, Newark, and Los Angeles, smaller communities are also affected. Even in rural areas, AIDS is on the rise (CDC, 1994).

Anyone can become infected with HIV. Unfortunately HIV is frequently associated with high risk behaviors that often result in social disenfranchisement and poverty. Although a disproportionate number of HIV-positive children are African-American and Hispanic, white, Asian-American, and Native-American children are also diagnosed with AIDS each year (CDC, 1994).

So what does this mean for the preschools and day-care centers? It means that preschool educators can expect the presence of an HIV-positive child. But the acceptance of an HIV-infected child in early childhood settings "will depend largely on the accuracy of AIDS knowledge and beliefs" of educators, parents, and other children (Jessee, Nagy, & Poteet-Johnson, 1993). Educators must take steps now to prepare for the increased numbers of HIV-positive children in the preschool setting. Even the possibility of an HIV-infected child in the classroom makes everyone else *affected*.

SOCIAL AND LEGAL ISSUES

"Please Be Our Friends"

> *"I would like everyone to know that please do not be scared of us, we have feelings too, it is not so easy to live with AIDS, be nice and treat us like everyone else. The worst thing about having AIDS is not knowing if people will be your friends. So please be our friends. We need you to be our friends."*
>
> Becky, age 8 (Weiner, Best, & Halpern, 1994).

Every child deserves to learn and play in a safe, nurturing environment. Children with HIV/AIDS deserve no less. They are the epidemic's most innocent victims, suffering not only from effects of the virus, but from prejudice and fear as well. Liss (1989) writes that "no other aspect of AIDS has generated more controversy, tension, and highly volatile emotional encounters than rumors that a child with AIDS is about to enroll or has enrolled in school."

In the early years of the epidemic, disease prevalence was highest among homosexual men and intravenous (IV) drug users, and the routes of transmission were not well understood. The social stigma and mystery attached to the disease transferred to infected children and led to efforts, many of them highly publicized, to bar HIV-positive children from school (Katsiyannis, 1992; Kirp, 1989; Ward, Fleming, & Buehler, 1994). The lawsuits which followed forced the courts to consider the constitutional and civil rights of everyone involved. The primary issues of concern have been the risk to public health and safety, protection from discrimination, and disclosure of HIV status. Overwhelmingly, the courts have supported the right of HIV-positive children to attend preschool and group day-care.

Public Health Recommendations

Recommendations from scientific organizations like the CDC, the American Academy of Pediatrics, and the American Public Health Association have stated that HIV-positive children can safely attend school because they pose only a theoretical risk to others, provided school personnel practice infection control and universal precautions (Black, 1986; Child Care Law Center [CCLC], 1994; Chanock & Simonds, 1994; Katsiyannis, 1992; J.F. Seidel, 1992).

Protection from Discrimination

Although no Federal law specifically prohibits discrimination against people who are HIV-positive, the courts have ruled that HIV-infected individuals can be considered disabled because of the social stigma and physical effects of HIV/AIDS. Therefore, children and preschool staff who have HIV/AIDS are protected under two key pieces of Federal antidiscrimination legislation: the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (Blackman & Appel, 1987; Katz,

1994; O'Hara, 1995; Seidel, 1987). Under these laws, publicly and privately funded child care providers cannot refuse to enroll an HIV-positive child. (Although church-sponsored programs are exempt under Federal regulations, they may be subject to inclusive State and local laws.) (CCLC, 1994).

Section 504 of the Rehabilitation Act of 1973 and its amendments of 1987 stipulate that agencies using Federal funds (including the U.S. Department of Education) cannot discriminate on the basis of disability. Additional protection against discrimination is provided by the Americans with Disabilities Act (ADA) of 1990 which extends the protections for disabled people to include to private organizations, like day-care centers.

Under Section 504, schools must make "reasonable accommodation" for students with disabilities. This "reasonable accommodation" clause has been controversial, but courts have decided that the "remote theoretical possibility" of transmission to others does not present enough of a risk to automatically exclude an HIV-infected child from group care settings or to isolate the infected child to protect staff and other children. The courts have also extended Federal antidiscrimination protections for symptomatic HIV-positive individuals to those who are asymptomatic (Blackman & Appel, 1987; Katsiyannis, 1992; Katz, 1994). Furthermore, preschools do not have the right to test a child for HIV or request information on the HIV status of a child or a member of the child's family (CCLC, 1994; Harvey, 1994).

Another Federal law, the Individuals with Disabilities Education Act of 1975 (Public Law 94-142), protects students who are already enrolled in special education programs at the time they become infected. The law stipulates that, based on the outcome of physical and cognitive assessments and input from parents or guardians, children should be allowed to receive an education in the "least restrictive environment possible." Consequently, schools can be sued if an HIV-positive child is isolated in a special education classroom (Fraser, 1989).

Disclosure of HIV Status

Issues related to confidentiality and the need to know are determined at the state and local level (Harvey, 1994; Ward, Fleming, & Buehler, 1994). All states require physicians to report AIDS cases to the state's public health department, and 27 states require reporting of HIV cases as well (CDC, 1994; Ward, Fleming, & Buehler, 1994). But there is wide variability in terms of reporting the infected child's identity (Katz, 1994). In some states and localities, information about HIV status may be disclosed to selected school personnel on a "need to know" basis to safeguard the health of the infected person and manage potential blood exposure situations. Those with a need to know are usually the school administrator or school nurse, and occasionally the teacher—although this varies according to state and local jurisdiction.

And while some states require that the public health department inform the school administrator about a student's status as soon as the department receives the HIV

test results; other states stipulate that HIV status can only be disclosed to schools with the informed consent of the parents or legal guardians (Harvey, 1994).

PREPAREDNESS OF PRESCHOOL EDUCATORS

Clearly, an HIV-positive child in class raises many challenges for preschool and day-care programs. To date, there has been no comprehensive effort to determine how well early childhood education settings are preparing for the presence of an HIV-positive child (J. Bogden [National Association of State Boards of Education], February 1995).

Indeed, our interviews with teachers, administrators, and parents indicate that most preschool policies are the result of having to face the issue of a known child with HIV/AIDS entering the class. These interviews indicate that policy, precautions, and education are generally done on ad-hoc basis rather than a systematic procedure that protects all individuals from physical and emotional hardship.

Public Schools (Grades K - 12)

However, public school districts, especially those in high HIV prevalence areas, are taking steps in this direction (Palfrey et al., 1994). Prompted by concern over lawsuits, most public school districts have developed policies that conform to CDC recommendations on disclosure and "need to know" (Holtzman et al., 1992; Katsiyannis, 1992; Kerr, Allensworth, & Gayle, 1989). A recent survey of the nation's 100 largest school districts (n=64) by Palfrey and colleagues (1994) found that nearly all (91 percent) had established written HIV/AIDS policies that address confidentiality and disclosure issues. However, because of these issues, it is hard to assess to what extent policies developed by school districts are being implemented at the school level. For example, while most school district policies contain guidelines on infection control, actual practice is inconsistent or lacking.

Despite the "earnestness of purpose" (Palfrey et al., 1994) of school districts to prepare for the presence of HIV-positive children, their efforts clearly are inadequate. Katz (1994) writes:

> *Although Federal legislation and judicial decisions are beginning to make headway in the fight against discrimination, local school districts and communities often lag far behind in implementing antidiscrimination measures and working successfully to alter attitudes.*

Staff preparation in the public schools is inadequate as well. In their survey of public school districts, Palfrey and colleagues (1994) note that "the complexities around maintaining confidentiality and the same time providing adequate services for children with HIV require special training and sensitivity." Although most teachers (88 percent) in the responding school districts had received some HIV-related training (the amount of training for kindergarten teachers was not

discussed), teachers were still concerned about having an HIV-positive student (Palfrey et al., 1994; Lavin et al., 1994). The investigators also found other school district staff to be inadequately prepared. Custodians and bus drivers received less HIV-related information than teachers, parents received even less, and food service workers received least of all.

These findings echo those of an earlier survey of preservice elementary school teachers (Ballard, White, & Glascoff, 1990). Although respondents believed they would eventually be teaching an HIV-positive child, less than one half said they knew how to avoid HIV transmission; one-third said they would feel at risk if they had to teach a student with HIV/AIDS. Another study of public school districts, conducted by Holtzman and colleagues (1992) concluded that the amount of time allocated for inservice HIV-education for public teachers (an average of two to four hours per year) was inadequate for the training to be effective.

Day-Care Centers

Far less is known about the readiness of day-care centers. Our exhaustive research has not identified any studies of day-care center HIV/AIDS policies or HIV/AIDS education of center staff. The fragmented day-care service delivery system has precluded any comprehensive assessment of group day-care settings (personal communication, P. Spahr [National Association for the Education of Young Children], March 1995).

The few studies that do exist indicate that day-care center staff are even less prepared that public school staff for the presence of an HIV-positive child. Day-care centers seldom train staff in child development and behavior or on how to care for a child who is chronically ill or disabled (Crowley, 1990; Willer et al., 1991). A study conducted by the Center for Career Development in Early Care and Education at Wheelock College (Morgan et al., 1993) found that state teacher certification (public preschools) and licensing requirements (private preschool programs) are inadequate to ensure that young children receive the care they need. (The study did not address HIV-related issues.) Moreover, any staff training programs that did exist varied widely in terms of content and amount of training.

Day-care centers need to offer staff training on a regular basis (personal communication, P. Spahr [National Association for the Education of Young Children], March 7, 1995). Because of the low salaries typical of most child care centers, staff turnover is high (Morgan et al., 1993; Willer et al., 1990). Staff who know little about infection control and other preventive health measures are less likely to consider them important enough to practice regularly (Calder, 1994).

BARRIERS TO PROACTIVITY

Misunderstanding about HIV Transmission

"I'm going to get it!"

Interview with a preschool teacher

Although the "hysteria syndrome" (Calder, 1994) which characterized earlier community responses seems to have abated, widespread concern remains that an HIV-infected children pose a health risk to others in the school setting. As Coles (1994) has noted, "Even well-intentioned people [tend] to insist on irrationally low levels of risk when their own health is at issue."

Concerns are understandable, but unfounded. Over a decade of intensive scientific scrutiny has demonstrated that HIV is only transmitted three ways: sexual intercourse with an infected person; injection or infusion of contaminated blood; and perinatally, from an infected mother to her child during pregnancy, delivery, or breast feeding (McIntosh, 1994). Among the more than 400,000 AIDS cases in the United States reported to the CDC, none has been attributed to any other type of exposure (CDC, 1994). Even though HIV has been found in saliva, urine, and tears, the amounts of virus are so minute that the risk is only theoretical (Chanock and Simonds, 1994).

"We've been studying this virus for well over ten years. Really intensively, in all sorts of ways, and if the worst case scenario you really worry about were to take place...we would have seen it by now. It hasn't happened."

(AIDS epidemiologist E. Gomperts, Pediatric AIDS Foundation video)

Moreover, there is no evidence that the behavior or activities associated with preschool settings places anyone—child or adult—at risk for infection. Studies conducted in schools and child-care settings have found no evidence of transmission, either child-to-child or child-to-adult, as a result of casual contact (Black, 1986; Rogers et al., 1990 in Jessee 1993). In studies of households in which infected adults and children lived, transmission did not occur as a result of the activities of daily living, even when the HIV status was unknown (Chanock & Simonds, 1994; Jones & Rogers, 1990; Liss, 1989).

HIV cannot be acquired by kissing an infected person, sharing a toothbrush, or drying their tears. It cannot be acquired by touching a soiled diaper or giving an HIV-positive child a bath. Nor can it be acquired by sharing food, eating utensils, and drinking glasses with an infected person. The virus cannot live in air; therefore, it cannot be spread by sneezing or coughing (Chanock & Simonds, 1994; Gerberding & Grossman, 1994; Jones & Rogers, 1990; Macklin, 1988).

Although HIV is carried in blood, no cases of AIDS have been reported as a result of bites (Chanock & Simonds, 1994). In child-care settings, the risk is even more remote, because the bite of a young child is unlikely to break the skin (Liss, 1989).

Concerns About Casual Contact

Jessee, Nagy, and Poteet-Johnson (1993) write that people are often unable to "differentiate between the severity of having the disease and the susceptibility to contracting the disease." Consequently, the perception of risk from casual contact remains widespread. A 1992 national survey of employed adults by the National Leadership Coalition on AIDS (1993) found that 67 percent of respondents thought their coworkers would feel uneasy working near someone with HIV/AIDS.

It is clear from our research that preschool educators and parents remain apprehensive about the presence of an HIV-positive child in the preschool setting. The misunderstanding about casual contact was summed up by one mother of an HIV-positive child:

> *To me, teachers don't have enough knowledge. The teachers wore gloves every day when I brought my son to school...It was crazy...seeing them wear gloves all the time!....People need to know that AIDS isn't easy to get"*
>
> Interview with a parent

Even when teachers and parents know how HIV is—and is <u>not</u> transmitted—they still can be uneasy about the risks associated with casual contact (Coleman, 1992; Epstein et al., 1994; Jessee, Nagy, & Poteet-Johnson, 1993; Kerr, Allensworth, & Gayle, 1989).

> *"Even if I tell them and they know the facts [about HIV/AIDS transmission], they just wouldn't understand. Then there are always people who wouldn't believe me or the facts."*
>
> Jamie, age 10 (Weiner, Best, & Halpern, 1994).

Despite the scientific evidence and intensive public education efforts (Katsiyannis, 1992), surveys of teachers and parents confirm that fear and misinformation about HIV transmission remain widespread. A survey of day-care centers, conducted by Morrow and colleagues (1991), found that more than 40 percent of parents and staff thought it possible that an HIV-infected child posed a risk to others at the center. In fact, nearly half of providers (48 percent) and parents (43 percent) responding to the survey were unwilling to be around, or let their child be around, a child with HIV/AIDS. Most respondents were concerned about exposure to the virus from biting or blood from a cut. But two-thirds thought the virus could be transmitted through tears, vomit, urine, and stool. Kissing an infected person and sharing food and eating utensils were also considered routes of virus transmission.

The perception of risk from casual contact is echoed in a later survey of day-care centers by Jessee, Nagy, & Poteet-Johnson (1993). They found that 68 percent of providers felt uneasy about caring for child with AIDS. Thirty-seven percent believed that individuals with HIV/AIDS should not work in school and child care settings; another 16 percent thought such individuals should be quarantined. The investigators concluded that "the more personal the idea of AIDS becomes, the more willing people are to consider stronger measures to control transmission."

EFFECT OF HIV/AIDS ON A CHILD'S PHYSICAL HEALTH

Children who have HIV/AIDS are not necessarily "doomed to brief lives of nothing but pain, suffering, and early death" (Meyers, 1994). Although most perinatally infected children show symptoms of AIDS by age three, the disease course is unpredictable. Some children progress rapidly to AIDS; other children experience only intermittent bouts of illness for several years. Still others remain healthy and symptom-free through late childhood and adolescence (Simonds & Oxtoby, 1995).

Opportunistic Infections

> *"It's a roller coaster ride—up and down hill—some days you can have a beautiful day with them (HIV-positive children) and maybe before the day is over you have to rush them to the doctor....But once you understand the illness, it's not so bad. It's something that you can deal with."*
>
> Foster parent of two young children with HIV/AIDS (Child Welfare League of America, 1991a)

Although the clinical situation varies with each child, HIV disease progresses along a continuum from asymptomatic HIV, to symptomatic HIV, and finally to AIDS. Symptoms of Pediatric AIDS include a failure to thrive, fatigue, low-grade fever, weight loss, diarrhea, coughing, and candida (oral thrush). The child experiences recurrent viral, bacterial, and parasitic infections which become more prolonged and more serious as the disease progresses. HIV-infected children develop illnesses like pneumocystis carinii pneumonia (PCP), cytomegalovirus, meningitis, and septicemia (Rubinstein, 1989).

It is important to note that classmates with intact immune systems are not at-risk for contracting the opportunistic infections which beset children with HIV/AIDS. The only exception being tuberculosis, which needs to be closely monitored in any classroom setting (Meyers, 1994). Conversely, HIV-infected children are very vulnerable to contracting diseases from their classmates. Normal childhood illnesses, like chicken pox and measles, represent a major health threat for the HIV-positive child.

Disabilities

> *"If my son goes to a park, 80 percent of the kids will run around. But my son can't walk right...he's too tired and can't do what the other kids do."*
>
> (Mother of 4-year-old child with HIV/AIDS, VSA Educational Services interview)

Chronic respiratory problems caused by opportunistic infections and the effect of the virus on the child's developing central nervous system can have a devastating impact on a young child's physical and cognitive development. Seventy-three to 90 percent of children with HIV/AIDS are born with or develop some form of developmental impairment (Susser in Jones & Martinson, 1990).

> *"It is difficult when your younger brother or sister grows faster than you do and you end up wearing their hand me down clothes instead of it being the other way around."*
>
> Becky, age 8 (Weiner, Best, & Halpern, 1994).

Fifty percent of HIV-infected children develop microcephaly (smallness of the head) which causes mental retardation (Rubinstein, 1989; Susser in Jones & Martinson, 1990). Twenty percent develop progressive encephalophy (brain damage). In fact, HIV/AIDS is becoming the primary infectious cause of mental retardation and developmental disability in children (Harvey & Decker, 1992 in O'Hara, 1995).

As a result of the virus and confounding environmental factors, like poor prenatal care or mother's drug use (Cohen et al., 1994; Rubinstein, 1989; J.F. Seidel, 1992), children also can experience language and speech problems, growth delays, emotional and behavioral disorders, vision and perception problems, and impaired motor skills (Papola et al., 1994; J.F. Seidel, 1992; Susser in Jones & Martinson, 1990).

The loss of previously attained functional milestones is also associated with Pediatric AIDS. This can be particularly frustrating for affected children. Although they may regain some of their functional abilities, they are never able to achieve new ones (Rubinstein, 1989; J.F. Seidel, 1992). Other children with HIV/AIDS reach a certain level of development, maintain it for a while, and then deteriorate rapidly (Cohen et al., 1994).

PSYCHOSOCIAL EFFECTS OF HIV/AIDS

Any chronic childhood disease raises a host of profound psychological and social issues. These are compounded when the disease is AIDS. Loss, prejudice, isolation, disruption—unfortunately, these experiences are all too common in Pediatric AIDS. HIV/AIDS has been described as a "horrifying burden" for HIV-positive children and their families (Belfer, 1986). They need compassion and understanding as they

try to cope with a disease that is stigmatizing, unpredictable, unrelenting—and ultimately fatal.

An HIV diagnosis is devastating news. Grief, anger, denial, and guilt are common reactions (Macklin, 1988). Parents may be overprotective; they may find it difficult to set behavioral limits or discipline their HIV-positive child (J.F. Seidel, 1992). Children, picking up on the parents' mood, are likely to become sad, anxious, or even angry.

Feeling anxious...

> *"...the child freaked out when he got a splinter. His sister was dying [from AIDS] at the time."*
>
> Interview with a teacher

Young children are likely to be confused by HIV/AIDS. Because of their level of cognitive development, they cannot fully understand why they are ill (Pontious, 1982; Schvaneveldt et al., 1990). They only know they are different. HIV-positive children tend to be smaller than their classmates. When they become symptomatic, they are sicker; they have to take medicine and they are absent a lot. Children who have HIV/AIDS visit the doctor frequently or stay in the hospital for long periods of time.

And as the disease progresses, children with HIV/AIDS may be unable to play and learn as their classmates do. The loss of abilities and changes in their appearance can leave an HIV-positive child vulnerable to teasing from other children (Belfer, 1986).

Feeling different...

> *"....I don't think it is very nice when people tease you. People have teased me because of my catheter and my backpack....Having AIDS is not fun, and I want the world to know that sometimes it makes you not feel very good and not want to do very much. We should not be teased about that either."*
>
> Hydeia, age 8 (Pizzo & Wilfert, 1994)

For preschool children "nothing happens by chance" (Belfer, 1986). Young children view the world in terms of absolutes: right and wrong, good and bad (Licamele & Goldberg, 1987; Pontius, 1982). They are likely to think that illness is the consequence of bad behavior. Therefore, a child with HIV/AIDS may blame him/herself for being ill. Depression, withdrawal, and anger are common reactions. Children with HIV/AIDS often need more reassurance and praise than other children (preschool teacher, VSA Educational Services interview).

Anticipating death...

"My mommy lives in heaven. Her eyelashes go down instead of up because she is dead...I think I am going to die too in a little while when I grow up. Like in 90 days or so."

Marilyn, age 4 (Weiner, Best, & Halpern, 1994)

HIV/AIDS is a "family disease" (O'Hara, 1995). Parents and siblings of HIV-infected children may also be infected. Frequently, HIV-positive children outlive their infected parents and end up living with extended family or in foster care (Meyers, 1994; Papola et al., 1994; Rudigier et al., 1990).

Feeling angry...

"The hardest thing about all of this is my brother. My brother is HIV and he bugs me....He gets a lot of attention especially when he almost died. Sometimes when he gets a lot of attention I feel left out...AIDS scares me because I am afraid that my brother will die. I always had a brother and I don't know how it would feel not to....I really want my brother to know that I love him even if I don't always show it. There are just some times that I have to hit him back."

Lauren, age 10 (Weiner, Best, & Halpern, 1994)

Families of HIV-positive children are under enormous stress: the anxiety produced by an HIV diagnosis; the burden from caring for a child who has a chronic, terminal illness; and the disruption caused by living with HIV—frequent visits to the doctor and emergency trips to the hospital. Families are frequently dealing with other issues as well. For example, the families of perinatally infected children are often disadvantaged and already struggling with poverty, poor housing, and inadequate access to medical and social services. Many are coping with a loved one's substance abuse. (Burr & Emery, 1994; Seibert & Olson, 1989).

Feeling sad...

...If only my mother and I didn't have HIV then my whole family wouldn't have to go through what they have to go through.

...If only my dad would be able to talk about us being sick.

...If only we didn't have to worry so much about money.

...If only my mom would stop being so stubborn and start taking medicine so she would not get sick.

...If only the world would be a more understanding place.

"If Only," by Dawn, age 11 (Weiner, Best, & Halpern, 1994)

Families often feel isolated. Because of the stigma attached to HIV/AIDS, many families are reluctant to "go public" (J.F. Seidel, 1992). The preschool and day-care situation may be one of the first times in which families must face the prospect of disclosing their child's HIV status, an additional source of stress for everyone involved (Twomey & Fletcher, 1994). The stress and isolation for African-American and Hispanic families is compounded by the dual stigma—the HIV diagnosis and racial/ethnic prejudice.

Feeling Isolated...

"I have AIDS and everyone is different than I am. It feels terrible to have AIDS because my tummy hurts a lot and because, if my friends find out, they wouldn't want to play with me"

Tanya, age 6 (Weiner, Best, & Halpern, 1994)

IMPLICATIONS FOR PRESCHOOL SETTING

A Safe, Nurturing Environment

"Some people treat you like you can't do this or you can't do that and ALL I want is to do things anybody else can do. Like climb monkey bars or big toys. I want to be normal. Don't you?"

BJ, age 10 (Weiner, Best & Halpern, 1994)

Preschool educators can play an important role in creating a safe, nurturing environment for children with HIV/AIDS. The preschool or day-care center can be a haven of stability and normalcy for the child with HIV/AIDS. The literature we reviewed, the parents we interviewed, and the experts we consulted all agreed that children with HIV/AIDS need as many normal childhood experiences as possible (Black, 1986; Rudigier et al., 1990). In most cases, this will be an easy task for the preschool teacher—teachers are usually unaware that an HIV-positive child is in the class. Many children who have HIV/AIDS look like and play as hard as their classmates.

If and when the child's HIV status becomes known to the teacher or when symptoms develop, the teacher should treat the HIV-positive child like any other child who has a chronic health problem or a developmental disability. A pediatric social worker interviewed by the Child Welfare League of America (1991b) noted that, apart from love, "one of the basic elements in caring for an HIV child...[is] accepting that the child is ill, has a disease, but for today, the child is well."

Children who are symptomatic may require less attention than, for example, a child with a hearing impairment. As one mother we interviewed remarked, "nothing

different happens at school...[My son's medications] are sent to the teacher. They're clearly marked. When it's time, he goes up to the nurse's office and takes the meds himself" (VSA Educational Services interview).

Preschool educators need not change their teaching methods. Dr. Allen Crocker of Boston Children's Hospital commented that teachers "just need to carry on....A child who has AIDS won't alter the classroom experience for other children—unless the teacher lets it." Speaking from experience as director of a nursery school that has successfully managed HIV-positive students, Mary Hartzell commented that "other than heightened awareness of the child's vulnerability, the preschool environment does not need to change to have a child with HIV." As a foster parent of a two-year-old child with HIV/AIDS explained:

> *The bottom line is the more you learn about the disease, the less fear you have...you don't have to worry about coming into contact with the child, you don't have to run around with rubber gloves all day. You just treat the child like a normal child.*
>
> (Child Welfare League of America, 1991a).

Knowledge About the Effects of HIV/AIDS

To work with HIV-positive children, educators need up-to-date information about HIV. They should be familiar with the full spectrum of HIV/AIDS—from asymptomatic infection to symptomatic infection to AIDS—and the implications of such a variable disease for the preschool setting (absenteeism, catheterizations, the severe consequences of normal childhood illnesses for an HIV-positive child). As Advisory Committee member Allen Crocker, M.D., (Harvard Medical School) noted, HIV is a "wild card...it manifests differently in every child....Teachers need to be sensitive to the changes that take place."

> *"Focus on the 'little victories'.... It's important that people who work with children with AIDS have reasonable expectations."*
>
> (Speech therapist, Child Welfare League of America, 1991b)

Teachers also need to understand what is—and is not—normal for a child with HIV/AIDS. For example, children who have HIV/AIDS often experience low-grade fevers and diarrhea, and the teacher need not be alarmed. With a solid understanding of the disease, preschool educators will be better prepared to identify and respond appropriately to the infected child's needs.

> *"I wish [the teacher] would talk to him when he's sad...explain to the other children why he wears braces."*
>
> (Mother of 4-year-old child with HIV/AIDS, VSA Educational Services interview)

In addition to knowing about the physical effects of HIV/AIDS, preschool educators need to understand the psychosocial implications for the infected child and the child's family. For example, Twomey and Fletcher (1994) write that attendance at preschool or day-care is especially meaningful to the parents of an HIV-positive child, symbolizing that "the child is progressing through life" and that the child's existence "consists of more than visits to the doctor and blood sticks."

Good Communications with Parents

Preschool educators should know the importance of maintaining frequent, even daily, communications with the HIV-positive child's parents (for example, through phone calls, notes, at pick up and drop off time) about the child's health status, especially in the case of symptomatic children who may have new health issues each day. On these occasions, the teacher can tell the parent about changes in the child's physical and emotional health or notify the parent about any contagious diseases (e.g., chicken pox) in the preschool.

Preschool educators should also ask parents if their infected child knows about his/her HIV diagnosis and how they want the issue handled should it arise in class.

Preschool teachers and day-care providers need to be aware of the implications for classmates and their parents. Some parents respond to the news of an HIV-positive child at school by threatening to withdraw their own child (Macklin, 1988; Putnam, 1993). Knowing about HIV/AIDS and having good communications skills will help preschool teachers manage parent concerns. Teachers need to be familiar with school policies regarding disclosure and infection control and be feel comfortable referring parents to a physician, nurse, or counselor for additional information.

Information About Infection Control

Because HIV is transmitted only through a few, very specific routes, preschool teachers and other school staff (custodians, bus drivers, food service workers) can prevent and control the situations that put children and themselves at risk. The CDC and the American Academy of Pediatrics have established guidelines on preventing the spread of infectious diseases (including HIV) in preschool and child care settings (AAP, 1992; Child Welfare League of America, 1991c). The guidelines consider hand washing and using disinfectants to be sufficient for preventing the spread of infectious diseases from body fluids that do not contain blood (e.g., tears, vomit, urine, feces, drool, nasal secretions).

For potential blood exposure situations, the guidelines recommend that school staff follow "universal precautions"; that is, using disposable latex gloves, a thick pad of tissues, or some other type of barrier between skin and blood. The practice of universal precautions is required under regulations established for employers by the Occupational Safety and Health Administration (CCLC, 1994).

"Infection control is good for everyone."

(Mary Hartzell, Director, First Presbyterian Day School)

There is some concern that following universal precautions presents a mixed message about the presence of HIV-positive children in the preschool setting (Lavin et al., 1994). But teachers and staff need to understand that these steps are needed to prevent other communicable diseases, like hepatitis B, as well as HIV. Furthermore, by practicing infection control every day and using universal precautions appropriately, preschools provide children with opportunities to model sound hygiene practices (AAP & APHA, 1992).

Positive Attitude of Teacher

To create the nurturing environment that all young children need, preschool educators must come to terms with their own attitudes and feelings about HIV/AIDS. A psychologist we interviewed noted that "getting beyond the fear is the biggest challenge." Three- to 6-year-old children are highly intuitive and easily pick up on adult anxieties (Burr & Emery, 1994). A positive attitude will not only help the infected child feel more secure, it is also key to fostering acceptance and compassion among the other children in the class (Burr & Emery, 1994; Wagman & Ludlow, 1988).

Even teachers who are comfortable with the subject of HIV/AIDS need to be aware of their emotional reactions to children with a terminal illness like HIV/AIDS. Some teachers may withdraw emotionally; others may find themselves being overprotective or too permissive (Belfer, 1986; Liss, 1989). The mother of a 4-year-old told us, "Don't make a big deal. Treat the child like any other child, let them do as much as they can on their own....and don't let them get away with things because they are sick!" Another mother we interviewed remarked that her 6-year-old's teacher "isn't worrying 'Will I get AIDS?' She's worrying 'When will the child die?' It's hard to talk to [the teacher] because she gets teary eyed." She added that teachers "need to look beyond the child's HIV and look at the child...and try to improve the child's quality of life."

Open Classroom Environment

Teachers should maintain an open atmosphere in which children feel comfortable asking questions about HIV/AIDS. Children may want to know why their friend is absent or why their friend is sick. To respond to questions appropriately, educators need to understand how a young child views illness and even why they are asking questions. According to Quackenbush (in Bush & Emery, 1994), children's questions about HIV/AIDS are motivated by a number of factors: They may have heard or seen the word "AIDS" and are curious. Or they may be concerned about becoming sick like their classmate. They may even ask about HIV/AIDS just to see if the question makes their teacher uncomfortable.

Instead of providing complicated explanations, preschool educators should respond in a way that is suitable to the child's level of understanding (Quackenbush, 1988;

Putnam, 1993). According to Mary Hartzell, "What young children really need to know about AIDS is that it's not something they can get. It's not like a cold."

The preschool setting should be a place where children feel free to talk about their feelings and experiences (e.g., "What was it like to go to hospital and have your blood drawn?"). Teachers should know techniques (e.g., play situations) to help children work through AIDS-related issues (e.g., death of classmate or parent) or understand concepts like disability and diversity. As noted by Lori Weiner, Ph.D., Coordinator of Pediatric HIV Psychosocial Support for NCI/NIH, children should know that "people are more alike than different."

WHAT PRESCHOOLS CAN DO

Importance of Proactivity

Because of the stigma associated with HIV/AIDS, parents may not choose to share their child's HIV-positive status with school staff (J.F. Seidel, 1992). And, as noted earlier, the legal requirements for disclosure vary among the states and local jurisdictions. Consequently, educators may not know that an HIV-positive child is attending their preschool.

In addition, there are many challenges for preschool educators when the HIV diagnosis is known. To effectively meet these challenges, preschool educators must be proactive, think through all the issues, and develop their own solutions.

Develop a School HIV/AIDS Policy

One way preschools can be proactive is to develop and implement a written HIV/AIDS policy. Schools that establish a policy in advance are in a much better position to avoid controversy and legal liability (CCLC, 1994; Harvey, 1994; Katsiyannis, 1992; Liss, 1989; McCormick in Walz, 1991). Schools that have an HIV/AIDS policy already in place will also be able to focus more effectively on the infected child's special physical and psychological needs, as well as the concerns of everyone else.

During a project Advisory Committee meeting, Jean Emery (Child Welfare League of America) observed that "having a school policy is not something brave and different...you're only doing what has been proven nationally you should do." Celestine Diggs-Smith (Head Start) agreed, saying "you don't create a policy because someone has AIDS. You do it to bring your school up to national standards—it's good for all the kids." Nancy Peddle (Board Chair, Ecumenical Child Care Network) concurred, adding "a lot of parents think 'my school is safe' but that's not the issue. A school policy for children with HIV is good for all children—it's just good practice."

The review of the literature reveals myriad recommendations and guidelines for HIV/AIDS school policies developed by professional organizations, such as the American Bar Association, National Association of State Boards of Education, the National School Boards Association, and Child Welfare League of America. These and the "Best Practices Guidelines" recently developed by the Children's Hospital in Boston, Massachusetts (Crocker et al., 1994), share several important considerations:

- **Practice Infection Control:** The school policy should provide staff with guidelines for practicing infection control and universal precautions. Kerr (1991) writes that by acting "as if everyone" is infected with HIV and taking the proper precautions, "there is no need to specifically know who is infected with HIV" or single them out for special care."

  Practicing infection control is easy and inexpensive. But it is only effective if practiced properly and consistently. Therefore, preschools should monitor staff compliance.

- **Conduct Periodic Assessments:** The school should work with a child's parents and physician to assess the child's health status, behavior, and functional ability, and then develop a plan to guide school personnel in caring for and working with the child. Because the child's health and developmental status may change, schools should conduct these assessments on an ongoing basis.

- **Maintain Confidentiality:** Confidentiality of an HIV diagnosis and HIV-related medical records should be maintained through a "need to know" policy that adheres to Federal, State, and local laws.

- **Form an Advisory Committee:** Involving the community in the HIV/AIDS policymaking is another way schools can be proactive. Such a committee should include teachers, school administrator, parents, and people with HIV/AIDS. Community involvement is beneficial for a number of reasons. First, it provides a way to educate parents and others in the community about HIV issues. A community advisory committee also offers schools an opportunity to build consensus of community support for the school's policy. Involving the community in policy development gives people an opportunity to think about the issues, discuss their concerns, and participate in the solution. "Just getting people to talk about AIDS is a first step" (Walz, 1991).

- **Obtain Advice from Legal and Medical Experts:** Developing a school HIV/AIDS policy can be a daunting process. Because the laws regarding disclosure of HIV status are so complex and confusing, many preschool educators are misinformed about their HIV/AIDS legal mandates (National Leadership Coalition on AIDS, 1993). In order to comply with the Federal, state, and local laws, it is critical that preschools consult with the Attorney General's office in their state on the HIV/AIDS policy (Katz, 1994; personal

communication, P. Walker [Kaye, Scholer, Fierman, Hays, & Handler, New York City], March 1995).

The preschool's community advisory committee should include medical experts (local pediatrician, public health official) to ensure that the school's HIV/AIDS policy reflects the most up-to-date scientific information.

- **Provide Staff Training:** Schools can be proactive by educating teachers and other school staff (e.g., custodians, food service workers) on infection control and other HIV-related issues. Studies show that inservice training is effective in enhancing teacher knowledge and encouraging positive beliefs about HIV/AIDS (Black, 1986; Ross et al., 1991). In addition, HIV-related training can provide preschool educators with tools they can use in other situations. Jean Emery and other members of our Design Team agreed that preparing for and working with an HIV-positive child presents an opportunity for preschool educators to expand their skills and become better teaching professionals.

  According to our Design Team, teachers need to know that they are "not in it alone." Therefore, schools can support teachers by providing them with resources: a school HIV/AIDS policy, school counselor, and school health professional. Schools can also support teachers and staff by providing them with the supplies and training they need to implement infection control (Kerr, 1991).

Implement Parent Education Programs

Schools with HIV-positive students report that well-informed parents are critical to successfully managing HIV-positive children in school (Palfrey et al., 1994). Educators should conduct ongoing parent education programs to inform parents about issues such as confidentiality and infection control, and reassure them about the safety of their child. Addressing parent fears directly in a question and answer helps parents process any concerns they may have. Jean Emery notes that "people want to do the right thing—if you can help them through the fear." In addition to allaying parent fears, this type of outreach helps ensure that the HIV/AIDS information children receive at school is consistent with what they learn at home.

Mary Hartzell recommends that every parent receive a copy of the school's HIV/AIDS policy at the time their child enrolls. Parents should be told how the school will handle enrollment of an HIV-positive student, as well as the school's procedures for infection control. She advises that schools emphasize to parents that "the steps being taken will benefit all children." Parents have told her that they believe their children are "safer in a school that has high health standards and practices rigorous infection control...that has a policy in writing for AIDS."

Schools can also support the parents of HIV-positive children. As Hartzell remarked, "these parents need to know that the school administrator will run interference for them."

CASE STUDIES OF SUCCESSFUL PROACTIVITY

Teamwork and a Plan

Successful responses to HIV/AIDS in schools have two common denominators:

1. the teamwork of administrators, teachers, and parents; and

2. a policy that protects the individual who is HIV-positive.

A case study on the experiences of an Ohio elementary school (Curtis, Morgan, & Broyles, 1994) describes how school administration and staff responded to a kindergarten parent's news that her child is HIV-positive. The report demonstrates how "teamwork" and an "educational plan" are central to helping an HIV-positive student feel accepted. First, the school principal checked to see if the school district had an HIV/AIDS policy: It did, but it was outdated and inconsistent with state law. Policy revisions included making the superintendent the "direct contact person" for all inquiries. This provision "helped cut down on the rumor mill and create a central information system." Next, the principal collaborated with the school's health personnel to devise a plan for informing staff about the presence of an HIV-positive child. Staff education was accomplished through a two-day inservice training program: The first day devoted to information on HIV/AIDS and a presentation by the child's mother; the second day offering staff an opportunity to ask questions and discuss their concerns. The staff reacted positively to the announcement, "almost as if they had always expected this would happen sooner or later."

The final step was to educate parents through a series of public forums, which featured presentations by AIDS experts, and private parent/teacher conferences. Intensive education efforts, which included inservice training for staff and a "town hall" meeting for parents. By the time the child's HIV status became public, parents also reacted positively.

The authors add that "to this day, everyone involved in this situation is truly amazed at what transpired over these nine or ten months. In truth, what we were experiencing was the result of an educated, informed group of people who were showing compassion and understanding for a little boy and his family."

Benefits of Proactivity

Members of our Design Team and Advisory Committee had personal experiences with community responses to disclosure of a child's HIV diagnosis. According to Lori Weiner, responses can range from the "most wonderful to the most ugly." All

of our experts emphasized that proactivity—through school policy development, infection control, teacher training, and community outreach—is key.

A case study from an elementary school in a suburb of Atlanta, Georgia, illustrates this point (Coomer, 1993). By the time a child with HIV/AIDS enrolled in the school, the principal had already realized that "it would only be a matter of time" before the school would have an HIV-positive student. Because of good planning by the school superintendent, school board, and principal, the presence of an HIV-positive child was met with equanimity by staff, parents, and students.

Two years earlier, the school district superintendent had devised a comprehensive policy to manage the attendance of HIV-positive students. "Armed with this support," the principal collaborated with school staff to develop a plan to protect the child's confidentiality, identify a teacher who would "accept the child like any other child," and educate staff and parents. For the first four months, the only other staff who knew the child's identity were the child's teacher, school counselor, and assistant principal.

The principal worked with the school district health coordinator to implement an education program for staff and parents. This consisted of a series of meetings in which AIDS experts answered questions about the disease. By the time school opened and child's presence was public knowledge, concerns over casual contact had been alleviated. The author reports that only one family requested that their child be transferred; this was denied by the school superintendent.

By the end of the school year, the burden of secrecy became too great for the child and he asked the school to reveal his identity. With support from his teacher and his mother present to answer questions, the child told his classmates about his HIV diagnosis during "show and tell." His classmates reacted with "curiosity and concern for him—not for themselves." They wanted to know "if it hurt to have AIDS." One child gave him a doll from her book bag. The author concludes that because a district policy already existed and staff and parent education efforts were undertaken immediately, "what could have been a harrowing experience, instead brought out the best in the school community."

MEETING THE CHALLENGE

Our Phase I investigations leaves no doubt. In the coming years, more HIV-infected children will be entering preschools and day-care centers all around the country. It is clear that the issues raised by HIV/AIDS are profound and complex. Fear and prejudice, community values and individual rights, illness, death, and loss—even the possibility of an HIV-positive child in a preschool or day-care center brings up all these issues. To meet these challenges, preschool educators need to be well-prepared.

Accommodating an HIV-positive child is not a religious or moral issue; in a sense, it is not even about HIV/AIDS. It is about having school policies that respect an HIV-positive person's legal rights. It is about having the knowledge and skills necessary to help children who have a chronic, unpredictable illness. And finally, it is about responding with compassion to children who are going through a difficult time.

As a result of our Phase I investigations, we are confident that the product we propose fills a real and pressing need. We are convinced that this product will go far in helping educators create a happy, healthy environment for all children, including those with HIV/AIDS.

CHAPTER 3

DESIGN PLAN

Based on the research findings and the outcome of our activities, VSA Educational Services developed a preliminary design for the proposed product. This chapter details both the rationale for and the outline for the design of the proposed training package. The chapter describes:

- The target audience;
- The basic considerations involved in the design;
- The principles that undergird the project;
- The basic outline of the content areas for the teacher and parent components; and
- The commercial application and dissemination plan.

The product described in this chapter represents a comprehensive package that will enable preschools and day-care centers to implement a proactive HIV/AIDS policy. The proposed package goes beyond a how-to policy manual and provides the needed educational components to prepare the staff, parents, and children to sympathetically and compassionately respond to a person with HIV/AIDS.

TARGET AUDIENCE

The research and interviews clearly show that even the possibility of an HIV-positive person in the preschool or day-care center makes everyone HIV *affected*. Therefore, our approach must be comprehensive and target the following groups:

- Preschool and day-care center administrators
- Teachers and other staff
- Parents of 3- to 6-year-old children and others in the community.
- Three- to-six-year-old children.

CONSIDERATIONS

The product will combine innovative technology and proven teaching techniques to help participants understand and process the information they receive. From our research and discussions with Design Team members, the product we create will incorporate the following elements:

Interactive: The literature on HIV/AIDS education, the preschool teachers we interviewed, and our Design Team all recommend training workshops as the best vehicle for teacher training. Gingiss (1992) writes that group training is particularly effective when participants are acquiring new skills and attitudes. Parent education is most successful in a forum in which participants can have their questions answered directly (Wagman & Ludlow, 1988).

The format will include opportunities for questions and discussion. By voicing their concerns and hearing other points of view, participants become aware of their beliefs and feelings. In the process, they can come to terms with any anxieties they may have.

Experiential: Much of the teacher training will be based on experiential learning theory, an approach recommended for preschool educators by the National Association for the Education of Young Children (DeVries & Kohlberg, 1987 in Coleman, 1992). By modeling skills presented by the trainer, use these skills to manage situations that could arise in the classroom. In addition by applying their knowledge in a "hands on" way, participants develop their own solutions to potential problems.

Engaging: We will use a mix of information dissemination and teaching methods to help participants understand and process the information they receive. Some recommended by our Design Team members include the following:

- Hook participants at the beginning with an "icebreaker" activity that encourages them to examine their beliefs and feelings about HIV/AIDS. Build trust by addressing fears at the beginning of the training.
- Use visuals (video, slides, and props) to demonstrate new skills, make points, and stimulate discussion.
- Use a flip chart to stimulate discussion and record participant responses.
- Use role playing activities to help teachers prepare for real life situations (death of child or parent, cleaning up after accidents that involve blood). These activities also provide them with an opportunity to practice good communications skills (e.g., teacher/parent meeting).

Personal: The Design Team corroborated what we learned from our interviews with preschool teachers and the parents of HIV-positive children: Personal stories

about HIV/AIDS-related issues have a profound impact. Therefore, the training will feature interviews with HIV-positive children, as well as parents and care givers. The Design Team also advised that factual information on the spectrum of HIV/AIDS (i.e., the difference between asymptomatic and symptomatic HIV) and virus transmission is more believable when delivered by an "expert" in the field.

Innovative: The training facilitator will use Level 1 videodisc technology to convey information and cue training activities and discussions. From our recent investigations (Reynolds et al., 1992) and our practical experience (through our "Music for All Children" program), we conclude that Level 1 videodisc technology is the most practical and effective way to meet our objectives. Videodisc technology offers many advantages. This technology is widely available and accessible in most school districts, and it is easy to use. Videodisc scenarios are linked by simple barcodes to the facilitator's training manual. Videodisc also offers flexibility. Facilitators can pick and choose what is shown, allowing them to modify their presentation.

We will also produce a videotape version. The costs will not be significantly increased, and the videotape greatly expands access to this product. Teachers and parents can take the videocassette home to review the information. In addition, videocassette versions of the program will make it more attractive for individuals, schools, and day care centers that may not have access to videodisc technology.

GUIDING PRINCIPLES

Our Design Team identified several key concepts which have guided product design. To be effective, the product must:

Emphasize that HIV/AIDS affects everyone: Participants must understand that any neighborhood, in any community, in any part of the country, can expect the presence of an HIV-positive child. To this end, information must be presented in a way that does not categorize HIV-infected people in terms of geographic location, gender, sexual orientation, race, or ethnicity. Unfair demographics only lead people to think that the presence of an HIV-positive child at school "could never happen to me." Instead, the program must stress that the factors that place people at high risk for infection.

Demonstrate that everyone benefits from an HIV/AIDS policy: The program must make clear that all children, not just those with HIV/AIDS, benefit from an open, nurturing environment and the daily practice of infection control.

Be comprehensive in terms of approach and delivery: The product should create an "armature" for good practice; that is, it should provide the framework that supports the presence of an HIV-positive child in the preschool setting. Our Advisory Committee stressed that an inclusive school HIV/AIDS policy should be the cornerstone of any school response HIV-positive students. The policy should

conform to Federal, state, and local legal mandates and respect an individual's right to privacy. It should also provide guidelines for infection control and encourage teacher and parent HIV/AIDS education.

To ensure that school administrators develop such policies, they need to be provided with "how to" manuals. As Nancy Peddle observed, "School administrators react with 'I don't know where to begin'....If they have a sample policy in front of them, they'll do it."

Product dissemination should also be comprehensive. The product should be available to public and private preschools, day-care centers, and other group care settings, as well as to parent and community organizations (e.g., PTA).

Be practical: Our research indicates that preschool educators need and want practical information to help them work with HIV-positive children. Therefore, the information presented must be relevant to everyday preschool activities. Training for teachers should demonstrate skills that can be adapted to a wide variety of HIV-related situations. It should also provide teachers with an opportunity to develop written plans to deal with HIV-related situations; for example, student questions about HIV/AIDS, angry parents, potential exposure situations.

In addition, the training product must be easy to use in a variety of school and community settings. It should also be designed for use in ongoing training efforts in settings where staff turnover is high (e.g., day care centers). Materials need to be developed "so it can be used for staff orientation each year."

Reinforce educational activities: The literature on staff development and HIV/AIDS education (Gingiss, 1992; Putnam, 1993) and the Design Team members advise that new knowledge, attitudes, and skills must continually reinforced: throughout the training itself and as a part of ongoing staff development. An Advisory Committee member Celestine Diggs-Smith noted that training "can't happen just once...You have to have components that can be used repeatedly."

Address misunderstanding and fear: Central to the success of the training is the recognition that even knowledgeable and well-intentioned people may have irrational fears about contracting HIV. Education for teachers, parents, and the community should focus on HIV/AIDS as a disease. To this end, training should 1) counter misunderstanding with facts, 2) reinforce the facts and reassure training participants, and 3) provide ways for participants to move from knowledge to belief.

PROPOSED PRODUCT DESIGN

Based on this target audience profile and these guiding principles, we propose to develop a comprehensive package of materials for preschools and day-care centers. Intended for individuals and organizations that work with preschool children (ages

3 to 6), the package will help administrators, teachers, and staff respond proactively to the needs of children with HIV/AIDS. The package will contain:

Policy manual: This manual will include a step-by-step process on developing and implementing a school HIV/AIDS policy. It will outline the legal requirements (e.g., the HIV-positive child's right to an education, confidentiality, etc.), supply guidelines for infection control, and define the roles of staff implementing the policy. In addition, the manual will provide tips for building coalitions with other organizations, as well as among staff and parents, to support implementation of the policy.

Teacher education: This inservice training component will consist of a videodisc, facilitator's manual, and participant handbook. It will provide teachers with the basic, knowledge, skills, and attitudes necessary to teach a child with HIV/AIDS in mainstream education setting. Special emphasis will be placed on allaying teacher fears.

In addition, a participant handbook will provide a quick reference guide for the teacher, which may be consulted when incidents arise in class.

Parent education: This component will consist of a videodisc, facilitator's manual, and fact sheet. It will be designed to mitigate fears of parents, explain what the school is doing to ensure infection control, and demonstrate that the HIV/AIDS policy is a means to ensuring the well-being of all children. It will also the formulation of policy in the context of legal requirements. The fact sheet will outline the school's legal obligation to the education and care of all children and provide information on HIV/AIDS, universal precautions, and infection control.

Child education: This component will be an illustrated "big book" that a teacher may use in the classroom to explain about HIV/AIDS, infection control, and universal precautions. This book will talk about HIV/AIDS in developmentally appropriate language which will help the class understand what is happening in the life of a classmate who has HIV/AIDS. In addition to general information, the book will contain stories about what is happening in the life of a child with HIV/AIDS: visits to the hospital, catheterizations, etc.). The book will encourage children to understand and empathize with one another.

MAJOR CONTENT AREAS

In outlining the major content areas for the comprehensive training package, the Design Team concentrated on the educational components. They noted that the content should first inform the audience about the basic facts about HIV/AIDS; then empower them to overcome fears and discomfort; and finally, encourage them to be proactive. Outlined below are the major content areas of both the teacher and parent education components:

Teacher Education Component

Introduction/Ice Breaker

Purpose:

To raise the awareness of what it means to be HIV positive.

Objectives:

1. To build trust among the participants to discuss openly the issues of HIV/AIDS with comfort and honesty.
2. To assess knowledge and attitudes of preschool teachers regarding this disease.

Unit 1: What is HIV/AIDS? Dispelling Fear with Facts.

Purpose:

To correct misinformation and to gain an understanding of the scope of HIV/AIDS.

Objectives:

1. To learn the definition of HIV/AIDS.
2. To gain a historical perspective on how the epidemic began and where it is headed.
3. To understand how HIV is transmitted and not transmitted.

Unit 2: What Should I Do? Minimizing Risks.

Purpose:

To establish the need and the practice of safe infection control.

Objectives:

1. To understand the need to assume anyone may be HIV positive
2. To outline the practices of infection control and universal precautions.
3. To reinforce the need for teaching health practices.

Unit 3: If a Child in Preschool has HIV/AIDS, What Does This Mean?

Purpose:

To introduce how HIV/AIDS affects the life of the child.

Objectives:

1. To outline the confidentiality issues.
2. To differentiate between the child who is asymptomatic and the child who is symptomatic.

3. To outline the various physical changes that may occur in a child who is symptomatic.
4. To outline the various cognitive changes that may occur in a child who is symptomatic.
5. To outline the emotional implications for the child.

Unit 4: If a Child in My Class has AIDS, How Does it Affect the Class?

Purpose:

To examine the role of the preschool teacher in maintaining a nurturing environment.

Objectives:

1. To demonstrate the importance of maintaining normality in the classroom.
2. To reinforce universal precautions and infection control as a regular practice.
3. To demonstrate ways to address issues surrounding the life of the child with HIV/AIDS.

Unit 5: Instituting Good Practice: Moving From Knowledge to Action.

Purpose:

To demonstrate how appropriate attitudes and actions support the school HIV/AIDS policy.

Objectives:

1. To use the knowledge gained in this training to shape personal emotions and actions about HIV/AIDS.
2. To use action, attitudes, and procedure to build support for the school HIV/AIDS policy among staff and parents.

Parent Education Component

Segment 1: What is HIV/AIDS?

Purpose:

To gain a basic understanding of the scope of HIV/AIDS.

Objectives:

1. To understand what HIV/AIDS is.
2. To gain a historical perspective on how the epidemic began and where it is headed.
3. To understand how HIV/AIDS is transmitted and not transmitted.

Segment 2: What is Being Done in the Preschool?

Purpose:

To demonstrate the preschool's response to HIV/AIDS.

Objectives:

1. To outline legal and confidentiality issues.
2. To understand the need to assume that anyone may be HIV positive.
3. To outline the practices of infection control and universal precautions.
4. To reinforce the benefit of increased awareness of infection control.

Segment 3: How is the Class Affected?

Purpose:

To assure parents that an HIV positive child does not put their child at risk.

Objectives:

1. To assure that interaction between children with HIV/AIDS and their classmates is safe.
2. To demonstrate that infection control instills the practice of good hygiene in children at an early age.
3. To encourage open communication and questions with children in regard to diversity and disability.
4. To teach positive life skills to all children.

COMMERCIAL APPLICATION AND DISSEMINATION

In researching the needs of preschools and day-care centers for the proposed product, we found not only a tremendous need, but also a overwhelming desire for such a product. Programs, like *Hugs InVited* and the *A Parents Town Meeting on AIDS* videotape, have served to excite a market among preschools and day-care centers. (See Appendix F: Additional Materials about HIV/AIDS.) Administrators of these programs state that these programs only introduce the issues related to HIV/AIDS and a more comprehensive package is needed that will help preschools and day-care centers systematically work through policy issues and education needs. As stated earlier, the producers of these products—Child Welfare League of America and Pediatric AIDS Foundation—along with other networks like the Ecumenical Child Care Network also indicate a strong demand among their constituencies for the proposed product.

This demand is spurred by the emphasis placed on HIV/AIDS education by such national professional groups as the National Association for the Education of Young Children and by state departments of education which are currently stepping up their licensing and accreditation requirements. Commercial preschools and day-care centers are increasing training of their teachers in response to these new

requirements and to stay competitive in an industry under increased scrutiny. The proposed program is also of interest to Head Start programs which can use their Federal training awards to purchase the programs, and to ensure that the program supports Head Start goals, we have involved Head Start personnel in all aspects of Phase I development and will continue this partnership in Phases II and III.

While most other preschools and day-care centers have limited funds for training, they can secure money for training through the Preschool Grant Program, Part B of the Individuals with Disabilities Act (IDEA). This program expands the IDEA requirement to provide a free and appropriate education to all eligible preschoolers, ages 3 to 5. The Federal contribution to the preschool program facilitates the continuity of services for children with disabilities moving out of the Infants and Toddlers program and before they enter first grade. Through Part B, money is given to the states, and states are mandated to distribute 75% of this money to the provision of direct services. The other 25% of the allocation is divided between discretionary funding (20%) and administrative costs (5%). Currently, the majority of states use their discretionary dollars to fund training or to purchase training materials.

The availability of these state, Federal, and other funds for training has led in part to our decision to collaborate with national networks like the Child Welfare League of America and the Ecumenical Child Care Network, whose constituencies are the community services organizations that run preschools and day-care centers for low socio-economic status children and families. These community services organizations can expend Part B funds to purchase the proposed package. In addition, we will continue to work with the professional organizations that represent early childhood education constituencies and institute a direct marketing campaign as part of Phase III to reach this national market.

Our proposed publisher, Redleaf Press, has identified a strong commercial market for the product and believes that it will also be in demand by Redleaf's international distributors. Redleaf Press is a non-profit press providing developmentally appropriate materials for the early childhood field. A division of Resources for Child Caring, its titles currently in print include the best-selling *Calendar-Keeper*, a record keeping system for family child care; *All the Colors We Are*, a bilingual children's book on how we get our skin color, and *Roots and Wings*, a multicultural curriculum. It publishes an annual catalog which is mailed to over 400,000 professionals (directors; teachers; college, university, and votech teachers; resource and referral staff; licensers; public health professionals; libraries; and day-care providers). It maintains the largest mailing list for family child-care providers and trainers in the nation, and has distributors in Canada and Australia. Redleaf has agreed to collaborate with VSA Educational Services in the development of the product. This collaboration will ensure the commercial success of the product. Indeed, Redleaf Press brings both an established national and international market to this project.

ANTICIPATED OUTCOME

By providing preschool and day-care settings with both a policy development tool and educational components, we can ensure that they have all the tools necessary to create a proactive, compassionate HIV/AIDS policy. The proposed package provides the means not only to educate all constituencies about HIV/AIDS, but to reinforce this education by repeated use of the training components. The flexibility built into the package will allow programs to incorporate both the policy suggestions and education components into the organization's existing policy and training activities.

APPENDIX A

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APPENDIX B

INTERVIEW INSTRUMENTS

HIV TRAINING FOR PRESCHOOLERS
INTERVIEW INSTRUMENT
FAMILIES

Interviewee:
Date:
Phone:
Fax:
Address:

A. Demographic Background for Families

A.1 Age of the child

A.2 Number of years since diagnosis

A.3 Is the child currently enrolled in preschool?

Number of years in preschool

Type of preschool (i.e., mainstream, special, etc.)

B. HIV-Positive Child

B.1 How do the needs of HIV-positive preschoolers differ from their peers?

B.2 What are the needs of preschoolers with HIV?

A: Physical

B: Developmental

C: Emotional

B.3 How should preschools and preschool teachers best meet these needs?

C. Preschool Teacher

C.1 What do preschool teachers generally know about AIDS?

C.2 Where do preschool teachers generally get their information about AIDS?

C.3 What do preschool teachers need to know about young children with the HIV virus?

C.4 What are the best ways to supply this information?

C.5 What are the concerns of teachers about having a child with HIV in their preschool class?

C.6 What are the best ways to address these concerns?

C.7 What knowledge, skills, and attitudes (KSAs) should a teacher possess to work with the family of an HIV-positive child?

C.8 What knowledge, skills, and attitudes KSAs should a teacher possess to address the concerns of parents of other children?

D. Classroom Environment

D.1 How are universal precautions implemented in the preschool classroom?

D.2 Who should know if there is an HIV-positive child in the classroom?

D.3 What preparations are needed to accommodate the HIV-positive child in the preschool class?

D.4 What adaptations need to be made in the daily activities of the preschool class?

D.5 What changes will the presence of an HIV-positive child bring in the content and ways the preschool class is taught?

D.6 How will the presence of an HIV-positive child affect the interactions between children in the class?

D.7 How do you prepare the class for the presence of an HIV-positive child?

D.8 What do preschoolers need to know about the HIV-positive child or AIDS?

D.9 How do you prepare parents for the presence of an HIV-positive child?

D.10 What do parents of non-infected children need to know about HIV-positive children or AIDS?

E. Training Needs

E.1 What are the best means to impart the necessary knowledge, skills, and attitudes to preschool teachers about children with HIV?

E.2 What is the best way to deliver this training?

E.3 How is this means of delivery different or similar to the traditional training of preschool teachers?

E.4 Would collaborative efforts with health care providers enhance the training?

E.5 What role do personal stories of HIV-positive children and their families have in the training?

E.6 What role can technology play in enhancing HIV training for preschool teachers?

HIV TRAINING FOR PRESCHOOLERS
INTERVIEW INSTRUMENT
EARLY CHILDHOOD EDUCATORS

Interviewee:
Date:
Phone:
Fax:
Address:

A. Demographic Background for Early Childhood Educators

A.1 Experience in early childhood education?

Years

Type

A.2 Experience working with children that are HIV-positive?

Years

Settings

A.3 Experience in teacher training

Years

Type

A.4 Experience in training development

Years

Type

B. HIV-Positive Child

B.1 How do the needs of HIV-positive preschoolers differ from their peers?

B.2 What are the needs of preschoolers with HIV?

A: Physical

B: Developmental

C: Emotional

B.3 How should preschools and preschool teachers best meet these needs?

C. Preschool Teacher

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C.2 Where do preschool teachers generally get their information about AIDS?

C.3 What do preschool teachers need to know about young children with the HIV virus?

C.4 What are the best ways to supply this information?

C.5 What are the concerns of teachers about having a child with HIV in their preschool class?

C.6 What are the best ways to address these concerns?

C.7 What knowledge, skills, and attitudes (KSAs) should a teacher possess to work with the family of an HIV-positive child?

C.8 What knowledge, skills, and attitudes KSAs should a teacher possess to address the concerns of parents of other children?

D. Classroom Environment

D.1 How are universal precautions implemented in the preschool classroom?

D.2 Who should know if there is an HIV-positive child in the classroom?

D.3 What preparations are needed to accommodate the HIV-positive child in the preschool class?

D.4 What adaptations need to be made in the daily activities of the preschool class?

D.5 What changes will the presence of an HIV-positive child bring in the content and ways the preschool class is taught?

D.6 How will the presence of an HIV-positive child affect the interactions between children in the class?

D.7 How do you prepare the class for the presence of an HIV-positive child?

D.8 What do preschoolers need to know about the HIV-positive child or AIDS?

D.9 How do you prepare parents for the presence of an HIV-positive child?

D.10 What do parents of non-infected children need to know about HIV-positive children or AIDS?

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E.2 What is the best way to deliver this training?

E.3 How is this means of delivery different or similar to the traditional training of preschool teachers?

E.4 Would collaborative efforts with health care providers enhance the training?

E.5 What role do personal stories of HIV-positive children and their families have in the training?

E.6 What role can technology play in enhancing HIV training for preschool teachers?

HIV TRAINING FOR PRESCHOOLERS
INTERVIEW INSTRUMENT
PHYSICIANS, CLINICIANS, AND PRACTITIONERS

Interviewee:
Date:
Phone:
Fax:
Address:

A. Demographic Background for Physicians, Clinicians, and Practitioners

A.1 Experience in Pediatric AIDS

Years

Specialty

A.2 Experience in training

Years

Type

A.3 Experience in training development

Years

Type

B. HIV-Positive Child

B.1 How do the needs of HIV-positive preschoolers differ from their peers?

B.2 What are the needs of preschoolers with HIV?

A: Physical

B: Developmental

C: Emotional

B.3 How should preschools and preschool teachers best meet these needs?

C. Preschool Teacher

C.1 What do preschool teachers generally know about AIDS?

C.2 Where do preschool teachers generally get their information about AIDS?

C.3 What do preschool teachers need to know about young children with the HIV virus?

C.4 What are the best ways to supply this information?

C.5 What are the concerns of teachers about having a child with HIV in their preschool class?

C.6 What are the best ways to address these concerns?

C.7 What knowledge, skills, and attitudes (KSAs) should a teacher possess to work with the family of an HIV-positive child?

C.8 What knowledge, skills, and attitudes KSAs should a teacher possess to address the concerns of parents of other children?

D. Classroom Environment

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D.4 What adaptations need to be made in the daily activities of the preschool class?

D.5 What changes will the presence of an HIV-positive child bring in the content and ways the preschool class is taught?

D.6 How will the presence of an HIV-positive child affect the interactions between children in the class?

D.7 How do you prepare the class for the presence of an HIV-positive child?

D.8 What do preschoolers need to know about the HIV-positive child or AIDS?

D.9 How do you prepare parents for the presence of an HIV-positive child?

D.10 What do parents of non-infected children need to know about HIV-positive children or AIDS?

E. **Training Needs**

E.1 What are the best means to impart the necessary knowledge, skills, and attitudes to preschool teachers about children with HIV?

E.2 What is the best way to deliver this training?

E.3 How is this means of delivery different or similar to the traditional training of preschool teachers?

E.4 Would collaborative efforts with health care providers enhance the training?

E.5 What role do personal stories of HIV-positive children and their families have in the training?

E.6 What role can technology play in enhancing HIV training for preschool teachers?

APPENDIX C

RESULTS OF INTERVIEWS

INTERVIEW PROCESS

To supplement its review of the literature, VSA Educational Services identified the top health care providers, practitioners, and researchers, as well as a sampling of parents, teachers, administrators, and advocates regarding HIV/AIDS issues. Interviewees were also representative of every region of the United States, located in 13 states and the District of Columbia. We then interviewed each at-length to determine information on the most current research, policies, and practices regarding HIV/AIDS issues as they relate to preschool and day-care settings. Interviews took an average of 1 to 1.5 hours. While structured to capture information on all the target questions, the interviews were flexible in order to allow the interviewees to expand on those areas in which they had the greatest experience. Through this variable format, we were able to learn much about the ongoing research, as well as the current level of knowledge among teachers and staff.

INTERVIEWS OF FAMILIES

HIV-Positive Child

The families stated that, depending on the individual child, the needs of the child with HIV/AIDS can be great, physically, developmentally, and emotionally. All stressed that they do not want their child treated differently from the other children. Teachers can best meet the needs of the children by gaining an education about the disease so that they are able to treat the child with HIV/AIDS as an individual and not as an HIV status.

Preschool Teacher

The perception of the families was that while preschool teachers have a range of knowledge about HIV/AIDS, the average teacher knows very little. All agreed that the teacher needs to have a lot of knowledge about HIV and its transmission, universal precautions, and specific information about the child with HIV/AIDS. The consensus among these families was that the families are the experts on their child's condition in terms of limitations, disabilities, and chronic conditions, and stressed the need for good communication between the teacher and the families. In addition to knowledge, the parents expressed that the teachers need to have a lot of

compassion when dealing with the family of a child with HIV/AIDS. When asked what were the concerns of teachers about having a child with HIV/AIDS in their class, the families gave a range of responses including fear that the teacher may catch the virus, fear of the child with HIV/AIDS' susceptibility to other illnesses, and concern that they would lose business if they accepted a child with HIV/AIDS into their preschool.

Classroom Environment

All families with children with HIV/AIDS agreed that the presence of a child with HIV/AIDS should not affect the daily activities of the preschool, the content and ways the preschool class is taught, or the interactions between children in the class. The only preparations that the parents perceive to be necessary to accommodate the child with HIV/AIDS in the preschool class are providing an education about HIV transmission including aspects of the disease specific to the child, i.e., use of a catheter.

INTERVIEWS OF EARLY CHILDHOOD EDUCATORS

HIV-Positive Child

Most of the teachers we interviewed were unaware of any special needs of the child with HIV/AIDS, physically, developmentally, or emotionally. The teachers felt that they could best meet any special needs by understanding the disease, by providing services geared toward the level of the child, and by being supportive.

Preschool Teacher

Most of the interviewees admitted that preschool teachers know very little about HIV/AIDS. Many had a basic knowledge of universal precautions and knew that they cannot get AIDS through casual contact. While some teachers get information from personal experience and workshops on HIV/AIDS, others get their information from the general media. When asked what were the concerns about having a child with HIV/AIDS in their preschool class, most said that they were afraid of either contracting the virus themselves or of other children contracting the virus through biting. Several teachers also expressed concerns about issues of confidentiality. Most teachers expressed a need to gain further information about HIV/AIDS to deal with a child with HIV/AIDS in the preschool class, the families of the HIV-positive child, and the families of other students.

Classroom Environment

All of the teachers stated that the presence of a child with HIV/AIDS would not greatly affect the classroom environment. When asked what preschoolers need to know about the child with HIV/AIDS, the interviewees gave a range of answers including telling the children nothing, teaching diversity, and teaching them everything about HIV/AIDS. When asked how to prepare parents for the presence

of a child with HIV/AIDS, again there was a range of answers including not telling them anything, just discussing universal precautions, and giving them a complete education about HIV/AIDS.

INTERVIEWS OF EXPERTS

HIV-Positive Child

While the experts identified many needs of the child with HIV/AIDS including medication, developmental delays, and issues of loss, they agreed that the needs of a child with HIV/AIDS depends on the child. The experts remarked that the teachers could best meet the various needs of the child with HIV/AIDS by gaining a full knowledge of the disease, knowing how to work with children with disabilities, and creating a safe, nurturing environment.

Preschool Teacher

The experts observed that teachers get their information about HIV/AIDS from a variety of sources, ranging from in-service trainings to the general media. All agreed that while what teachers know about HIV/AIDS varies, all have some knowledge of its transmission and universal precautions. The experts perceived that teachers have a range of concerns about having a child with HIV/AIDS in the classroom including fears that they will be infected, concerns about the safety of other children, specifically about biting, and concerns about dealing with disabilities in the classroom. All experts agreed that preschool teachers need to understand specific information about young children with HIV/AIDS such as the differences between the asymptomatic versus the symptomatic child; the impact of chronic illness; and issues of loss for this age group. The experts feel that teachers need the following knowledge, skills, and attitudes to work with the family of a child with HIV/AIDS and the family of other children: accurate information about HIV/AIDS, knowledge about the individual child's disease, cultural competency training, skills in discussing grieving and loss, information about confidentiality laws, sensitivity, compassion, and love of all children.

Classroom Environment

All interviewees emphasized the need for preschool teachers to meet each child in the classroom exactly where he/she is; to assess special needs regardless of knowing HIV status, thus placing the emphasis on the child rather than the disease. The experts feel that preschool children should have the following information about HIV/AIDS: what to do in case of an injury, information about health and illness, and information about germ and germ transmission. Several experts expressed that any information provided to children should be provided on their developmental level. When asked what parents of other children need to know about HIV/AIDS, the experts gave a range of answers including just information about universal

precautions, providing a general education about HIV/AIDS, and conducting a parent meeting allowing parents to express their fears.

APPENDIX D

DESIGN TEAM MEETING MINUTES

DATE AND LOCATION

Wednesday, January 11, 1995, Washington, DC, at the offices of VSA Educational Services.

PARTICIPANTS

James Bodgen, M.P.H. (Project Associate, National Association of State Boards of Education)
Patricia Davenport (HIV/AIDS Consultant, VSA Educational Services)
Jean Emery, LICSW (AIDS Curriculum Developer, Child Welfare League of America)
Mary Hartzell (Director, First Presbyterian Nursery School, Santa Monica, California)
Karen Hennessy, RN, CPNP (AIDS Specialist, VSA Educational Services)
David D. McKinney, Ph.D. (Principal Investigator, VSA Educational Services)
Patricia Spahr (Director of Information Development and AIDS Education Coordinator, National Association for the Education of Young Children)

PURPOSE OF MEETING

Participants met to discuss and reach consensus on the design and content of a program to help preschool educators prepare for and work with students with HIV/AIDS.

MEETING SUMMARY

During the meeting participants talked about the information needs of preschool educators with respect to Pediatric AIDS and identified program content areas. They also discussed approaches for addressing topics and possible formats for training delivery.

The meeting began with an overview of the project and a report on research activities to date. Participants heard the results of telephone interviews conducted with parents of children with HIV/AIDS, early childhood educators, and experts in child development, HIV/AIDS education, and teacher training. The survey

findings underscore the importance of providing a safe, nurturing environment for all preschool children, in which child with HIV/AIDS is treated no differently than any other child. The findings also clearly demonstrate that preschool educators need practical information to help them prepare for and work with HIV-positive students. Issues of concern include the routes of virus transmission, controlling and/or preventing HIV infection in the preschool setting, and the effect of HIV/AIDS on a preschool child's physical, cognitive, and emotional development.

During the ensuing discussion, the group identified a number of issues that should be addressed in the training materials. These are noted below.

ISSUES TO BE ADDRESSED

HIV/AIDS Affects Everyone

HIV/AIDS affects everyone: the infected child, parents, classmates, and preschool administrators, teachers, and other staff. Because of the wide ranging implications of introducing a child with HIV/AIDS in the class, the preschool teacher should be aware of all the issues relating to HIV/AIDS. They should know about the physical, cognitive, and emotional effects of HIV/AIDS on all preschool children, the different needs of asymptomatic and symptomatic children with HIV, and the implications for the preschool setting (e.g., medication, absenteeism, other illnesses like chicken pox). They should also be familiar with what is—and what is not—normal for a child with HIV, (e.g., low grade fever, diarrhea, etc.).

In addition to the physical issues, preschool educators should be aware of the emotional consequences of HIV/AIDS on an infected child's and classmates' families. They should also be cognizant of their own feelings about the HIV-positive child and how such feelings could affect their behavior toward the child (e.g., over-protectiveness, anticipation that the child will die, treating the child in a way that isolates him/her). Educators should be aware of the fact that preschool children are intuitive and pick up on teacher attitudes and anxieties.

In addition, the program should present HIV/AIDS demographic information in a way that does not categorize HIV-infected people in terms of an ethnic/racial group. This could result in unfair demographic labeling as well as lead to program participants believing that "it [HIV] could never happen to me." Instead, the program should address the factors that place people at high risk for infection.

Importance of Proactivity

Since HIV can be invisible and parents may not disclose a child's HIV status, the program should stress the importance of proactivity—through appropriate infection control and a school policy that safeguards all children, ensures confidentiality for children with HIV/AIDS and their families, and protects against discrimination—

and demonstrate that such proactive steps protects the health of all students and staff.

Educators must know how to practice appropriate infection control and follow universal precautions. Besides helping to prevent HIV/AIDS, infection control in the preschool setting also helps to control the spread of all communicable diseases. Moreover, educators who implement infection control provide children with important lessons in health education and opportunities to model sound hygiene practices.

Proactivity also means that teachers should prepare plans for dealing with a variety of potential AIDS-related situations (e.g., student questions about AIDS, angry parents, biting incident).

Importance of Open and Nurturing Environment

The preschool setting provides the child with HIV/AIDS with stability and as many normal childhood experiences as possible. Preschool educators can play an important role in creating a safe, nurturing environment. The program should stress that a child with HIV/AIDS should be treated like any other child with a health problem. Other than a heightened awareness of the child's vulnerability, the preschool environment should not change. Participants stressed that the classroom environment is both physical and psychosocial:

Physical environment: Very little has to be done to the physical environment. Universal precautions and infection control are important to the health of all children and should be used in the class regardless.

Psychosocial environment: Teachers should maintain an atmosphere in which children feel they can talk about their feelings and experiences (e.g., "What was it like to go to hospital and have your blood drawn?"). They should know techniques (e.g., play situations) to help children work through AIDS-related issues (e.g., death of classmate or parent). Educators also should know how to talk about HIV/AIDS in a way that is appropriate for a child's developmental level.

Preschool educators should be reminded that having an HIV-positive student does not change their basic teaching method. HIV-positive children do not require special attention on daily basis, unlike other children with chronic health problems or disabilities (e.g., hearing loss, braces).

Importance of Good Communications

The program should stress the importance of good communications with all parents. For example, give all parents a copy of school's HIV/AIDS policy. Good communications will also help educators manage parent concerns; for example, information on the school's infection control practices, and having a physician, nurse, or counselor available to respond to questions.

It should also provide suggestions for increased communications with parents of children with HIV/AIDS. Educators should know the importance of maintaining frequent, even daily, communications with parents (e.g., phone calls, notes, conversations during pick up and drop off) about the child's health status, especially in the case of symptomatic children who may have new health issues each day.

Need for School HIV/AIDS Policy

To effectively meet the needs of students with HIV/AIDS, preschool teachers need the support of the school. This support should include: a school policy that addresses all communicable diseases (not just AIDS), safeguards confidentiality, and protects the student against discrimination; help in answering parent questions, access to school counselors; and supplies necessary to follow infection control practices.

School support is also important for parents of HIV-positive children. Parents need to know that the school administrator "will run interference for them." In addition, teachers should be reassured that they are "not in it alone" and have a variety of resources from which to draw: school HIV/AIDS policy, school administrator, school counselors, professional organizations, health education materials.

Need for Education as Part of a School HIV/AIDS Policy

In order for a school's HIV/AIDS policy to be successful, preschool educators should be comfortable with the subject of HIV/AIDS, have a solid knowledge base about the disease and an understanding of how the disease affects the child and the child's family, and know the techniques for controlling infection and managing the emotional and social issues that accompany the disease. This information is particularly important in light of issues which are unique to the preschool setting. These include: parent/child separation issues, high level of physical contact between child and teacher (e.g., hugging, help with toileting), etc.

This approach also gives preschool educators the tools to use in other situations. Preparing for and working with an HIV-positive child presents an opportunity for preschool educators to expand their skills and become better teaching professionals.

The program should also address the fact that teachers and staff do not work in a vacuum. An effective school HIV/AIDS policy requires the support of well-informed parents and others in the community. Central to the success of the program is the recognition that even knowledgeable and well-intentioned people may have irrational, but valid fears about contracting HIV/AIDS. Education for teachers, parents and community members should counter misunderstanding with facts, reinforce the information and provide reassurance throughout the training program, and provide ways for participants to process their fears. "People want to do the right thing—if you can help them through the fear." In fact, working through fears about AIDS is an essential part of implementing a school HIV/AIDS policy and preparing the classroom environment for HIV-positive children.

PROPOSED PRODUCT DESIGN

Meeting participants agreed that a comprehensive package on HIV/AIDS should be developed for preschools and day-care centers. Intended for individuals and organizations that work with preschool children (ages 3 to 6), the package will help administrators, parents, and teachers and staff respond proactively to the needs of children with HIV/AIDS. Participants proposed that the package be based on the creation of a comprehensive school HIV/AIDS policy.

The creation of the HIV/AIDS policy would involve education components for teachers, parents, and children with special emphasis will be placed on allaying fears. Training strategies mentioned in the meeting included:

- Building trust by addressing fears at the beginning of the training.
- Outlining the facts about HIV (e.g., how it is transmitted, the history of the disease, the difference between the symptomatic and asymptomatic child, effect of HIV on the immune system). This information should be reinforced throughout the training.
- Providing opportunities for teachers and parents to voice their concerns (e.g., biting), process the information, and come to terms with any anxiety. Address "worse case" scenario by acknowledging "anything can happen" and following up with a realistic example.

In addition to its use in the formation and implementation of an HIV/AIDS policy, the education components could also provide inservice training and a participant handbook could provide a quick reference guide for teachers when specific incidents arise in class.

SUGGESTIONS FOR PROGRAM DELIVERY

Meeting participants advised using a mix of teaching methods to help teachers and parents understand and process the information they receive. Noted below are some of the strategies they mentioned.

General Strategies

- Hook teachers and parents at the beginning with an activity that relieves stress and exposes feelings and perceptions.
- Provide them with opportunities to ask questions, voice their concerns, and process the information (e.g., role play activities).
- Intersperse videodisc segments with interactive training activities. Use videodisc scenarios illustrate problems and solutions and to cue activities and discussions.

Teacher Specific Strategies

- Use role playing activities to help teachers prepare for real life situations (death of child or parent, cleaning up after accidents that involve blood) and provide them with an opportunity to practice good communications skills (e.g., teacher/parent meeting).

- Provide teachers an opportunity to develop plans to deal with AIDS-related situations.

APPENDIX E

FOCUS GROUP MINUTES

DATE AND LOCATION

Monday, February 13, 1995, Washington, DC, at the offices of VSA Educational Services.

PURPOSE

The Focus Group was convened to test both the content and delivery mechanism for the proposed education components of the training package. The Group was composed of parents, teachers, and administrators of preschool and day-care centers. They were asked to participate in a sample module for the proposed training. Like the proposed education component, the module consisted of a series of interactive exercises, video-based presentation, and facilitator-led discussion. The following narrative describes the session.

SAMPLE MODULE

The sample module was facilitated by Karen Hennessy, RN, CPNP. She began with an activity geared toward getting the participants to openly discuss their concerns about HIV/AIDS. Upon entering the room, the participants were given a piece of paper with "+" or "-" on it. The participants were then asked to create a list of "the craziest thing you have ever heard about AIDS." Participant responses included that you could get AIDS from hugging, from donating blood, and from children's shoelaces. The participants were then asked to identify whether their paper had a "+" or "-," what they felt the labels meant, and, after the pieces of paper were identified as HIV status, how they felt when hearing these crazy notions about HIV transmission. Ms. Hennessy then guided them through a discussion about the differences between rumor and fact, and the group identified the harmful effects of rumors including fear, prejudice, and stigma.

Using video freeze frame, a definition of AIDS was displayed on screen, followed by a video segment in which a medical expert discussed HIV, AIDS, and the transmission of the virus. The expert also touched on the practices of infection control. Ms. Hennessy followed up on the expert's presentation by further discussing HIV transmission, infection control, and by answering questions put to her by participants.

Next, Ms. Hennessy introduced the topic of the child with HIV. She demonstrated that HIV can affect the child from head to toe but stressed that the appearance of HIV in the child is as individual as the child him/herself. She explained that the child with HIV progresses from asymptotic to symptomatic to death. In order to put a human face on the disease, Ms. Hennessy showed a video segment of a child with HIV/AIDS discussing her disease, how it feels to be teased, and what makes a good friend. Following the segment, participants were asked if the child was asymptotic or symptomatic. Although many of the participants identified the child as asymptotic, she is in fact symptomatic. Ms. Hennessy pointed out that the child was wearing a backpack containing a catheter, giving the child a continuous infusion of medication. Through freeze frame and the use of a doll, the topic of caring for a symptomatic child, specifically one with a catheter, was introduced.

The presentation then moved from the child to the classroom environment. Half of the participants were given a worksheet that said "Preschool is important for children because . . ." The other half was given a worksheet that said "Preschool is important for the child with HIV because . . ." Both groups were asked to finish the sentence. Ms. Hennessy then compared the responses of all participants and found that the answers were all similar. The group reached the conclusion that preschool is good for the child with HIV for the same reasons that it is good for all children.

During the presentation, the group was encouraged to ask questions and respond to what was being presented. The following observations were made during the presentation. After being presented with information about HIV transmission, the group expressed fear regarding the means of transmission of the virus. Although it seemed that the participants understand and are implementing correct infection control procedures, they wanted reassurance that they are in fact protected from infection. Likewise, after being presented with visuals about an HIV-positive child who uses a catheter, the group expressed concerns about the care of the catheter. One of the participants wondered what emergency indicators look like and what is normal for the child. All participants expressed that in terms of classroom environment, there is no real difference in the way they would treat children with HIV/AIDS than other children in the classroom.

FOCUS GROUP REACTIONS

Following the presentation of the sample module, David D. McKinney, Ph.D., entered the room and asked the group to respond to open-ended questions geared toward getting their reactions to the presentation. Dr. McKinney began by asking the group to respond to the information on HIV/AIDS received during the training. The group responded that the information was very useful. It was a very good combination of concrete and non-concrete information about HIV/AIDS.

Dr. McKinney then asked if they felt that the presentation was relevant. They responded that it was relevant. One participant responded that the presentation put the child with HIV/AIDS in perspective. Another participant responded that the

presentation pointed out that all children, regardless of HIV status, have the same needs.

The following question asked if the presentation inspired the participants to be proactive in their approach to HIV/AIDS issues. Many expressed that it did inspire them to be proactive. The group also expressed concerns on how to ensure parents that their children would be safe and how to teach their students about HIV/AIDS and the affects it may have on their peers.

Participants responded favorably to the question about the use of a physician presenting factual information about HIV/AIDS. One participant stated that unconsciously, it would make a difference in the way the information was accepted.

Dr. McKinney asked the participants to respond to the specific activities in the presentation. Overall, the responses were good. The participants did express some confusion about the initial icebreaker and recommended that the presenter supply more information prior to beginning the activity. They appreciated the activity about preschool being important for children with HIV and felt that the 'rumor vs. fact' activity would help them better deal with anything outrageous they might encounter about HIV transmission.

All participants stated that they would recommend this training package to others.

APPENDIX F

ADDITIONAL MATERIALS ABOUT HIV/AIDS

MATERIALS TO TEACH CHILDREN ABOUT HIV/AIDS.

The "Come Sit By Me" video/teaching guide and storybook (AIDS Media 1993, 1994) is designed to help parents and teachers discuss HIV with 4- to 8-year-old children.

The poster "Keen Cat," developed by the Delaware Department of Public Instruction (Dover, Delaware), features cartoons illustrating how HIV cannot be transmitted.

"Tell Me About AIDS," developed by the American School Health Association (1992), is a package of materials—guides for parents and teachers and a workbook for children in grades K-6.

The White Earth Reservation Tribal Council (White Earth, Minnesota) has developed a coloring book or grades K-3 called "AIDS: Boozhoo! Do You Know That You Can't Get AIDS From...."

A videotape, "Thumbs Up for Kids," Media Express, Inc. 1989) teaches 3- to 8-year-old children about disease and infection.

MATERIALS FOR PARENTS

Videos and discussion guides produced by the Pediatric AIDS Foundation seek to reassure parents of classmates of HIV-positive children and teach parents how to a child's questions about HIV/AIDS.

Video/discussion guide packages developed by the Child Welfare League of America (1991a, 199b) target prospective foster parents of children with HIV/AIDS patients.

The San Francisco AIDS Foundation (1988) has published the brochure "Your Child and AIDS" to reassure parents of public school children.

The monograph, "HIV/AIDS: Images of Hispanic Youth" (American Red Cross 1990), contains interviews with 6- to 17-year-olds who have had a family member with HIV.

MATERIALS FOR PRESCHOOL EDUCATORS

Teacher Education

Another monograph, "Does AIDS Hurt?: Educating Young Children About AIDS" (Quackenbush and Villarreal 1992), targets teachers and care providers.

"Meet the Somebodies," developed by the Iowa Department of Education (Des Moines, Iowa 1989) is a curriculum for teachers in preschool through first grade. It features posters and music for a song that stresses that every child deserves to be somebody even if the child has HIV.

A manual, "Healthy Young Children" for program planners includes a section on HIV and is available from the National Association for the Education of Young Children (Kendrick, Kaufmann and Messenger 1991).

Getting a Head Start on HIV: A Resource Manual for Enhancing Services to HIV-Infected Children in Head Start, developed by the National Pediatric HIV Resource Center.

School Policy Development and Infection Control

"A School Leader's Guide to AIDS Education," developed by the National School Boards Association (1989) emphasizes advocacy for HIV education in schools and provides guidelines for school policy development and developing HIV curricula.

The Association for the Advancement of Health Education and the Council for Exceptional Children (Byrom and Katz 1991) also provides information on HIV and guidelines for developing HIV education programs and policy.

Another guide, developed by the Child Welfare League of America (1991c), "Serving Children with HIV Infection in Child Day Care," discusses HIV-related medical and psychosocial issues, the importance of developing an HIV policy and practicing infection control.

The Redlands Christian Migrant Association (Immokalee, Florida 1990) has developed a manual on HIV for staff of child care centers.

"Someone at School Has AIDS," developed by the National Association of State Boards of Education (Fraser 1989), provides state and local policymakers with sample school guidelines, information on performing health assessments of staff and children with HIV, and information on infection control.

Another set of "Best Practices Guidelines" were recently developed by the Children's Hospital in Boston, Massachusetts, under a grant from Maternal and Child Health Bureau, for the project "Supports for Children with HIV Infection in School" (Crocker et al., 1994). These guidelines stress the importance of developing a school policy that respects the infected person's right to privacy and safeguards

confidentiality; training staff about HIV-related topics such as virus transmission, legal rights, and infection control; creating a learning program that is based on the child's needs, not on the status of the child's HIV infection; and linking with PTAs and other organizations too teach parents and families about these issues.

There are other resources that provide information on how to implement infection control. The Center for Health Training and the National Association for the Education of Young Children have manuals on how to follow universal precautions.